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## Cognitive aspects of chronic fatigue syndrome

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## **Abstract**

Recent interest in cognitive behavioural therapy techniques for treatment of Chronic Fatigue Syndrome (CFS) has highlighted the contribution of psychological approaches to alleviating the debilitating symptoms of this illness. In previous research sufferers from CFS have been compared with depressed patients and patients with neuromuscular disease, as they share similar symptoms, but not diagnosis. This study attempts to compare four groups including a normal working group. A new measure was developed and piloted, designed to measure interpretations of symptoms in CFS. In addition standard instruments were used to focus on the measurement of high personal standards, perfectionism, emotional control and conscientiousness and levels of autonomy.

Results showed the CFS group were similar to the normal working group on all standard scales and scored low on autonomous personality traits. Reasons for this result, and the clinical implications for treating such a heterogeneous patient group are discussed. Measures on the symptom interpretation scale show CFS patients are less likely to give an emotional explanation for their symptoms than the other participant groups. This has implications for communication between physician and patient, and the treatment of CFS with a psychological model.

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## **1. INTRODUCTION**

### **1.1 AREA OF INVESTIGATION**

Recent interest in cognitive behavioural therapy (CBT) techniques for Chronic Fatigue Syndrome (CFS), has highlighted the contribution of psychological approaches to alleviating the debilitating symptoms of this illness, and in elucidating its aetiology. This dissertation sets out to examine recent investigations into personality profiles of CFS sufferers, the relationship this may have with their interpretation of symptoms, and possible effects on maintenance of the problem.

### **1.2 OVERVIEW**

As an introduction to the Chronic Fatigue Syndrome a description of its symptoms and an account of the history of fatigue as an illness will be given. This will introduce theories which have been attached to the syndrome over the last century, and will help explain the controversies which surround the condition.

The discussion will focus on the cognitive behavioural model of CFS and its influence on approaches to treatment, especially in relation to depression. The relationship between attributional style, personality and illness perceptions are particularly important in relation to coping style and prognosis. The importance of communicating such illness perceptions to doctors, will remain a theme throughout this dissertation, as the manner in which symptoms are discussed can have an effect on diagnosis and treatment.

This will lead to an evaluation of research with CFS sufferers, and also those who are thought to be suffering from similarly unexplained illnesses, such as irritable bowel syndrome (IBS) and chronic pain (CP). The discussion of methodological issues and implications for this study will lead to a statement of the aims and hypotheses to be investigated.

### **1.3 DEFINING CFS**

Chronic Fatigue Syndrome (CFS) was first operationally defined as recently as 1988 (Holmes,

Kaplan, & Gantz) and was rapidly redefined in 1994 (Fukuda, 1994) in order to encompass subsequent advances in medical and psychiatric research. It has become a topical and controversial illness and is regarded as a medically unexplained syndrome by physicians (Sharpe, 1996).

### 1.3.1 The 1994 Consensus

The definition of CFS used for this study conforms to the 1994 consensus (Fukuda, 1994). A case definition for CFS, by the 1994 consensus, does not try to identify a new disease but represents a working definition of a clinical problem, pending further understanding. Furthermore it attempts to link medical and psychiatric thinking about the problem. The diagnostic criteria are summarised in Table 1.

**Table 1.** *Case definition of CFS (1994) from Sharpe (1996)*

<b>Inclusion criteria</b>
Clinically evaluated, medically unexplained fatigue of at least 6 months' duration that is Of new onset (not life long) Not a result of ongoing exertion Not substantially alleviated by rest A substantial reduction in previous level of activities The occurrence of 4 or more of the following symptoms Subjective memory impairment Sore throat Tender lymph nodes Muscle pain Joint pain Headache Unrefreshing sleep Postexertional malaise lasting more than 24 hours
<b>Exclusion criteria</b>
Active, unresolved or suspected disease Psychotic, melancholic, or bipolar depression (but not uncomplicated major depression) Psychotic disorders Dementia Anorexia or bulimia nervosa Alcohol or other substance misuse Severe Obesity

The nature of fatigue syndromes<sup>1</sup> have been the subject of debate since the 1860s, (Beard 1880) Beard published an account in his *Practical Treatise on Nervous Exhaustion* (1880). He named the disease Neurasthenia from the Greek for “lack of nerve strength”. The chief symptoms were “undue fatigue on the slightest exertion, both physical and mental...with other symptoms of headaches, gastrointestinal disturbance, and subjective sensations of all kinds.” Fatigue was the first and most important symptom, Neurasthenics had “abnormally quick fatigability and slow recuperation” (Wessely, 1991). Beard acknowledged that it was a subjective experience with the symptoms being “slippery, fleeting and vague”, but insisted nonetheless that it was as real a disease as small pox or cholera (Woods & Goldberg, 1991).

*‘In strictness, nothing in disease can be imaginary. If I bring on a pain by worrying by dwelling on myself, that pain is real as though it were brought on by an objective influence.’* (Beard, 1880)

However the description and diagnosis of fatigued states has remained controversial up to the present day. Whether it is the lack of objective clinical signs and the subjective nature of the experience (Blocq, 1894; Sharpe, Archard & Banatvala, 1990), or the continued lack of proof for its pathogenesis, chronic fatigued states have attracted a variety of medical definitions which have been particularly influenced by the social and cultural elements (as well as the state of scientific knowledge) of the time (Wessely, 1991). This is still true of contemporary accounts of fatigue within our own and different cultures; neurasthenia as an organic condition still flourishes in China and India and is the reason for the retention of the name in the current International Classification of Disease (ICD-10) even if not used internationally. (Abbey & Garfinkel, 1991; Kleinman, 1982; Showalter, 1997).

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<sup>1</sup>The terms neurasthenia, ME, PVFS, CFS and others will be used as the authors of the time used them. All will be used in a neutral fashion to reflect changing understanding of fatigued states by doctors and historians.



## **1.4 PREVALENCE AND PROGNOSIS IN CFS**

Fatigue is a common presenting problem in primary care (David, Pelosi, & McDonald, 1991). Prevalence rates for CFS have been quoted between 7.4 and 37 per 100,000 depending on the sampling procedures and diagnostic criteria used (Moss-Morris, 1996). The average age of onset is approximately 30 years with well-educated white women being over represented in patient samples (Gunn, Connel, & Randall, 1993). However it has been diagnosed in all age groups including children (Dale & Straus, 1992). Short term prognosis for recovery of function is poor but improves with time. Most patients make a functional recovery by two years, 23% may still experience symptoms and 11% still be functionally impaired at 2-4 years following onset of symptoms (Sharpe, Hawton, Seagroatt & Pasvol, 1992).

## **1.5 A HISTORY OF THEORIES OF FATIGUE**

A history of fatigue (Wessely, 1991) follows the controversy of fatigued states from Beard to the present day. Theories of fatigued states have moved from the physical theories of neurasthenia, (Beard, 1881) heavily influenced by Victorian attitudes towards the differing roles of the sexes in society and the rigid class system (Abbey & Garfinkel, 1991); to psychological theories which carried pejorative associations including; hypochondriasis (Edes, 1895), somatic symptoms of depression (Wilson, Widmer, Cadoret, & Judiesch, 1983) and mass hysteria (McEvedy and Beard, 1970).

Freud was instrumental in dismembering the category of Neurasthenia into new psychiatric diagnoses, especially anxiety and depression. However he also continued to believe in a physical neurasthenia, but thought that it was rare (Wessely, 1991). The first issue of the Journal of Abnormal Psychology criticised the “futility of the purely anatomical concept” and in its place suggested a psychological model for neurasthenia of personality disintegration (Donley, 1906). Shands & Finesinger (1952) suggested that fatigue marked a narcissistic regression from the external world.

Scientific developments in identifying infectious diseases and their treatment and the new

science of immunology, also lent their weight to etiologic theories of fatigue. Success in identifying postinfective conditions in the neurological field, especially that of post infectious encephalomyelitis (Kabat, Wolf & Bezer, 1947) fuelled efforts to identify a viral cause for fatigued states. Fatigue was associated with the Epstein-Barr virus (EBV) (Straus, Tosato, Armstrong, Lawley, Preble, Henle, Davey, Pearson, Epstein, Brus, & Blaese, 1985) from the 1980s, the human herpes virus-6 (Wakefield, Lloyd, Dwyer, Salahuddin, & Ablashi, 1988), and enteroviruses (Archard, Bowles, Behan, Bell, & Doyle, 1988). Although these studies remain inconclusive (Swanink, Melchers, Van Der Meer, 1994) at present the search for a viral cause continues, and it has been suggested that the virus is a new one not yet isolated (Abbey & Garfinkel, 1991).

The focus of pathophysiological research in the 1990s (Sharpe, 1996) has included viral infection, immune dysfunction, sleep abnormalities, cardiovascular and respiratory abnormalities, neuroendocrine abnormalities, neurotransmitter abnormalities, and brain imaging. No single pathophysiologic process has been conclusively identified as a cause of CFS. However recent developments show a difference in neurotransmitter and neuroendocrine changes in CFS and depressed patients, results are still pending (Bearn, Allain & Coskeran, 1995).

More recent research has taken an anthropological approach to fatigue, and has considered the role of somatic experience and the social course of the illness within specific cultures (Ware & Kleinman, 1992). It is beyond the scope of this study to incorporate illness interpretations from other cultures, the study will confine itself to the predominantly white caucasian patient group found in this country.

## 1.6 CURRENT CONTROVERSIES

Patients' opinions about the aetiology of the fatigue have often differed from that of established medical science. However theory about the relevance of immune dysfunction to the aetiology of and persistence of fatigue are shared by patients and some of the current medical profession, and

are championed in the current self help literature. They also provide an historical continuity with Beard's description of "overload" from the environment. Current theories of immune disorganisation cite environmental toxins, dietary toxins, internally generated autointoxicants, and the effects of widespread antibiotic use as causes of fatigued states triggered by stress or a virus (Steincamp, 1989).

Both self-help books and the media have tended to emphasise disease explanations for the symptoms of CFS at the expense of more psychiatric or psychological ideas (Fisher, 1989; MacLean & Wessely, 1994). An extreme view point from a self help book expressed a conspiracy theory of professionals denying the existence of CFS/ME instead falsely labelling the problem as psychological (Ostrom, 1989). The media interest in fatigue especially in the late 20th century has taken up these issues, particularly as the subject is linked with a modern reaction against medical authority and paternalism and hence "makes a good story."

MacLean found that many stories were fuelled by, but also contributed to, the stigma of psychological disorder and the dualistic thinking in medical literature; whether the illness is in the body (an organic problem) or the mind (a psychological problem). She also argues that press coverage "contributes to the polarised and unhelpful nature of many encounters between patients with the chronic fatigue syndrome and their doctor, as frequently described in the self-help literature." There is a "highly charged medical, social and political atmosphere surrounding the subject" (Reeves, Pellett & Gary, 1992).

## 1.7 SUMMARY

Thus social and cultural elements as well as scientific and medical developments have influenced the understanding of fatigue. Diagnoses have accumulated meaning within these contexts, some positive and some pejorative. The story of CFS is also the story of how doctors and patients view each other, through contemporary social and cultural ideas. This aspect of the history of fatigue, in combination with dualistic thinking, has dominated much of the writing on the aetiology of fatigue, and has produced extreme views expressed by both doctors and patients.



Current clinical work on CFS attempts to be more objective in the observation and description of symptoms and patients characteristics. The application of CBT theory to clinical observations will be discussed in the next section.

## **1.8 CURRENT CLINICAL OBSERVATIONS WITHIN A CBT FRAMEWORK**

A recent systematic clinical observation of over 100 patients, Surawy (Surawy, Hackman, Hawton & Sharpe, 1995) working within a CBT framework, described clinical features common to the majority of CFS sufferers and similar to those Beard noted. These included not only the patients physical symptoms but also aspects of the patients emotional presentation, specific illness beliefs, behaviour, personality and pre-morbid lifestyle, and psycho-social difficulties associated with the onset of illness. Symptoms included physical and mental fatigue exacerbated by activity, poor concentration and memory, muscular pain, breathlessness and dizziness. There was a relative absence of expressed distress despite the presence of somatic symptoms typically associated with anxiety and depression. When anxious or depressed mood was expressed it was typically reported as a consequence of the fatigue; frustration was often expressed spontaneously at the inability to do things.

Surawy observed that most patients believed that their illness was due to a physical disease; suggestions that the illness could be caused by psychological or social factors was usually resisted, however exploration of the resistance revealed that psychological problems such as depression were regarded as indicating weakness, fault or blame worthiness. Symptoms were regarded as indicators of worsening disease process and activity was therefore avoided when it exacerbated symptoms. Patients were rarely concerned about the possible presence of a serious hidden disease (other than the CFS) and not at all concerned about the illness being life-threatening. Behaviour was typically inactivity with repeated bursts of activity to attempt pre-morbid levels of performance. These failed to achieve the intended aim and exacerbated symptoms, and were thus followed by return to inactivity.

Surawy interviewed patients' families who described the patients' pre-morbid personality



as marked by achievement orientation, perfectionism, and high standards for work performance, responsibility and personal conduct. Patients also described coping with emotions by "bottling up feelings" and "putting on a brave face". They placed great value on the opinion that others held of them. Their pre-morbid lifestyles were characterised by striving to meet both their own high standards and the expectations of others.

Onset was usually described as occurring at the same time as a viral infection. Surawy found that on further enquiry major psycho-social stressors and difficulties preceded the illness. These included chronic relationship and work difficulties, bereavement and difficulty negotiating life changes. These difficulties often remained unresolved many months after the onset of illness.

Research in the 1990s has focused in many different areas in an attempt to specify the aetiology of CFS. A trend away from dualistic thinking and towards a multi axial approach to CFS has recently developed as a consequence. This supports Surawys approach which investigated the interaction of cognitive, behavioural, physiological and social factors in precipitating and perpetuating the illness. The next section will summarise research which seeks a multi-axial approach to the problem and will examine the relationship with depression within this picture.

## **1.9 CREATING A MULTIAXIAL APPROACH TO CFS**

It has been recognised in clinical practice that both organic and psychological contributions often occur in the same patient (David, Wessely & Pelosi, 1988) and it is the interactions between these variables that gives CFS its clinical complexity. Swartz, (1988) believes CFS may prove to have multiple causes, psychological status potentially having an impact on both physical vulnerability and the response to the illness, and in turn being affected by the illness. Ray (1991) is concerned with the psychoneuroimmunological approach which considers the interconnections between emotions and behaviour, the central nervous system and the immune system. She also considers it misleading to assume that viral, immunological and psychological explanations are rival hypotheses. Potentially variables may have a reciprocal influence leading to a vicious circle and cumulative decline of functioning; and that CFS may prove to be a heterogeneous condition, with

different combinations of factors producing symptoms in different cases. Ray warns against discarding hypotheses on the basis of inconsistent findings, and to be alert to anomalies of data which may be masked when these are considered as a whole.

In order to overcome methodological difficulties for research and diagnosis into psychological factors within such a complex picture as CFS, Jenkins (1991) proposes a multi-axial system using axes for physical illness, psychological illness, social difficulties, personality and illness behaviour (Table 2).

Thus not all the patients' symptoms are required to fit a single diagnosis. Jenkins believes it is vital to diagnose psychological abnormality, not on the negative grounds of absent physical abnormality, but on the positive grounds of the presence of psychological phenomena, and to place the psychological phenomena in their multi-axial framework. Having recorded the presence or absence of abnormality on each of the five axes, to complete the descriptive picture of the patient's clinical state, the next step is to, where possible, describe aetiological and maintaining factors.

**Table 2.** *A multi-axial framework for diagnosing CFS (Jenkins, 1991).*

	Physical	Psychological	Social	Personality	Illness Behaviour
I	Antecedent predisposing factors				
II	Direct causes				
III	Pathogenic processes caused by the etiologic agent				
IV	Manifestations of the disease				
V	Treatment				
VI	Factors affecting prognosis				

Using such a multi-axial framework in patients with CFS it is possible to include on the physical axis chronic viral infection, perhaps in the gut but affecting other sites, including muscle and the brain; on the psychological axis symptoms of abnormal mood and cognition, some of which may be a result of viral infection of the brain, or the result of secondary depression following viral illness, and some which may antedate the onset of viral infection and perhaps have been a contributory factor to the host susceptibility; on the social axis there may be a number of antecedent and consequent acute and chronic social problems and lack of support; on the personality axis there may or may not be pre-existing abnormal personality traits; on the illness behaviour axis there may be normal and abnormal behaviours. "It is essential that research is planned and interpreted on such a multi-axial framework if erroneous deductions from observed associations are not to be made" (Jenkins, 1991). An example of such research is (Blakely, Howard & Sosich, 1991) which correlated ~~of~~ psychometric typology with biological changes in patients with CFS and with Chronic Pain (CP) .

Areas of psychoneuroimmunological investigation have included the influence of somatization, attributions, perceptual processes, coping behaviour, personality characteristics, and stigma and bias (Sharpe, 1996).

### 1.9.1 Depression and CFS

One manifestation of CFS has been interpreted by physicians as depression. It is now possible to consider the question of depression within a multi-axial framework without losing sight of other factors within the whole picture of the Chronic Fatigue Syndrome.

Ray (1991) presents possible interpretations of the role of depression in CFS. She considers several possibilities:

- a. that the rates of depression are inflated by the fact that somatic symptoms which characterise CFS are also criteria for depression, and that many widely used assessment measures such as the Beck Depression Inventory include these;
- b. that the depressive symptoms observed in CFS patients could be a direct result of the

pathophysiological function of a medical condition such as a viral illness;

- c. that CFS is a reaction to the chronicity of the illness and its impact on functioning;
- d. that depression might play a contributory role in the onset of CFS, 50% of one patient sample had a major depressive episode prior to developing fatigue, (Taerk, G.S. Toner, B.B. Salit, I.E. Garfinkel, P.E. & Ozersky, S., 1987) or a perpetuating role in an illness precipitated by a virus. Here a depressive reaction to an illness might lead to avoidance of activity, and mood disorder might sustain symptoms;
- e. that psychological vulnerability can affect susceptibility to viral illness (Cluff, Canter & Imboden, 1966);
- f. that the symptoms of CFS are a manifestation of psychological distress, given the high rate of depressive and other psychological disorders in these patients (Wessely & Powell, 1989).

In the following section evidence that CFS is a manifestation of psychological distress, particularly depression, will be reviewed. Further to this, aspects of personality, attitudes to somatic symptoms in CFS and their interaction with illness behaviour will be considered. This will not rule out the other factors on the multi axial table but will seek to define the influence these cognitive and personality factors may have within the complete picture of the Chronic Fatigue Syndrome.

## **1.10 SYMPTOMS OF CFS AS A MANIFESTATION OF DEPRESSION**

Wessely and Powell (1989) in a comparison of CFS with neuromuscular and affective disorders, found a rate of 72% of psychiatric disorder, including 47% major depression, in the CFS sample, compared with 36% of the neuromuscular group (using criteria which excluded fatigue as a symptom). There was no difference in subjective complaints of physical fatigue between all groups. However mental fatigue and fatigability was equally common in CFS and affective patients, but only occurred in those neuromuscular patients who were also cases of psychiatric disorder, suggesting that fatigue in CFS resulted from a central mechanism.

Wessely observed that CFS patients more closely resembled affective patients overall than



neuromuscular patients. The symptoms of CFS had little ability in Wessely's judgement to discriminate between CFS and affective disorder. The principle difference between matched CFS and psychiatric controls was attribution of symptoms to physical rather than psychological causes in the former. The vast majority of CFS patients rejected the idea that psychological factors were wholly or mainly responsible for the illness.

Wessely ruled out the possibility that the affective changes in CFS patients were simply a reaction to a chronic state of ill health, as the neuromuscular group had been ill for an equivalent length of time, and the rate of psychiatric disorder was significantly higher in the CFS group. Further increased length of illness was not associated with increased physical fatigue or mental illness.

However Wessely also noted that not all cases of CFS could be explained by depression. Forty-seven percent of CFS patients were cases of affective disorder, but 25% had other psychiatric diagnoses and 28% had no psychiatric disorder. However 10 of 13 without psychiatric disorder had disturbance of sleep and/or appetite. Hypothalamic dysfunction is important in disorder of mood (Wehr 1988)(Wehr, Rosenthal & Sack, 1988) and a similar common pathway may exist in CFS.

In this study the role of infection within the CFS group remained unclear. Seventy-two percent of CFS patients felt their illness had commenced with a virus, but no symptomatic differences emerged between those with or without history or evidence of a precipitating viral illness. Wessely suggested that the link between virus and fatigue operates via recognised psychiatric disorder in the majority of cases, and by a "still unknown central mechanism in even more cases." Short term prospective studies have demonstrated that psychological disorder is a predictor of length of illness following influenza (Imboden Canter & Cluff, 1961) and EBV (White, 1989a). Wessely concluded that CFS was a heterogeneous condition where "depressive illness is a sufficient, but not necessary, explanation."

White (1989b) in a review of psychiatric disturbance in CFS patients concluded that a third of patients with CFS showed no evidence of psychiatric disorder. This cluster of patients without

significant psychiatric symptoms agrees with that of Blakely *et al.*, (1991) who identified a degree of heterogeneity amongst CFS sufferers. At one extreme was a large group who did not describe themselves as psychologically deviant. In comparison with other subgroups of CFS sufferers MMPI measures showed they were over-controlled (low Impulsivity and Hostility) and defensive (high Denial). Consistent with this they denied experiencing psychiatric symptoms (had low depression and anxiety scores on the GHQ and BDI) whilst strongly endorsing the presence of CFS symptoms. This conforms closely to the ICD-10 (1989) description of Neurasthenia, where despite the presence of fatigue, weakness and exhaustion after minimal effort, depression and anxiety are absent.

### 1.10.1 Attributional Style and Depression in CFS

In a study to determine illness perception and symptom components in CFS Ray (Ray, Wier, Cullen & Phillips, 1992) defined four symptom components; emotional distress, fatigue, somatic symptoms and cognitive difficulty. Fatigue, somatic symptoms and cognitive difficulty contributed directly to the patients' perception of illness severity, but negative emotions did not. These findings support the view generally expressed by patients that mood disturbance is not a feature of the illness with a similar status to fatigue and other symptoms.

According to attribution theory (Kelley, 1967) outcomes tend to be attributed to factors with which they covary. Ray observes that "a lack of independent relationship between emotional states and perceived severity could be one subjective basis on which patients de-emphasise their pertinence and attribute their illness primarily to physical rather than psychological causes." However, despite the fact that CFS sufferers did not make a direct link between emotional distress and illness severity Ray found negative emotions did correlate with other symptom components. Ray argued that this correlation reflects a reciprocal influence with negative emotions exacerbating fatigue and other key symptoms and the debilitating nature of these symptoms enhancing emotional vulnerability.

Powell (Powell, Dolan & Wessely, 1990) compared CFS sufferers and depressed patients



for depressive phenomenology and attributional style. In common with other studies CFS patients tended to attribute their symptoms to external causes and depressed patients to internal causes. CFS sufferers experienced very little self-blame or lowered self-esteem compared with depressed controls; instead those CFS sufferers who satisfied criteria for depression did so largely by virtue of mood change together with weight, appetite and sleep disturbance, somatic symptoms and anhedonia. Thus the groups were similar in measures of affective and biological symptoms but differed in cognitions relating to self-worth. Powell considered this external attributional style to be exerting a protective influence against certain cognitive changes of depression, as opposed to an internal style of attribution causing the patient to experience greater psychological distress and lower self-esteem. External attribution also protected the patient from being exposed to the stigma of being labelled psychiatrically ill.

However the detrimental aspect of this external attributional style, especially when the fatigue is seen by the sufferer as untreatable, may lead to helplessness, increased fatigue, lack of self efficacy and diminished scope for self help (Wessely, David, Butler & Chandler, 1989). The result corresponds to those predicted by the "learned helplessness" theory of depression (Seligman, 1975). Ray (1991) suggests that CFS may be a particular subtype of depression where the patient avoids self blame by attributing symptoms to a physical rather than a psychological illness.

Interestingly this theory links with the more psychodynamic approach of Shands (1952) who described the chronically fatigued patient as holding an ideal self-image, and a concept of self in relation to others, which must be protected by passive behaviour or a narcissistic regression from the external world. Shands noted the difference between the depressed patient and the fatigued patient; the former attributed impoverishment of the ego to the self, the latter attributed this to agencies in the outside world.

### **1.10.2 Personality and attributional style**

Surawy's observations (1995) about pre-morbid lifestyle and her presentation of the cognitive aspects of CFS, support the theory of a personality who may be more vulnerable than others to the current social emphasis on achievement and to the cultural stigma associated with psychological problems. The conscientious, perfectionistic, high achiever (Abbey & Garfinkel, 1991) may respond to a situation in which they are unable to attain self imposed standards of performance. This may include chronic adversity or such as being over stressed or blocked in a career, and factors that reduce the internal capacity for performance such as depression due to loss.

This characteristic profile has been described by Beck (1983) as the "autonomous personality". He has suggested that depression in such achievement oriented people takes a different form from that seen in the sociotropic, or relationship focused person, and is characterised by the rejection of help, pessimism about recovery and a greater concern about the ability to perform. Patients with CFS share many of these characteristics but differ as they rarely report low self-worth. Surawy agrees with Ray (1991) that it is the disease attribution that protects the CFS patient from this. She further argues that the disease attribution for the symptoms tends to be maintained by its effect in reducing the social blame and loss of self-esteem which would be experienced if the patients' situation were seen as failure to perform, or of depression. This blame reducing function may also explain why the disease attribution is defended by patients and patient organisations. The next section will address the relationship of illness perceptions to coping style and prognosis in CFS.

### **1.10.3 Illness perceptions, coping style and prognosis**

Recovery from CFS has been shown to be independent of virology (Wilson, 1994), and immunological measures, and a poor outcome to be related to psychological morbidity (Sharpe, Hawton, Seagroatt & Pasvol, 1992). Those who remained the most disabled and psychologically impaired compared with other sufferers, and had the worst outcomes, believed CFS had an entirely infectious aetiology and that the illness was out of control, and advocated complete rest. (Wilson,



Hickie, Lloyd, Hadzi-Pavlovic, Boughton, Dwyer & Wakefield, 1994). Thus disease attribution appeared to be a stronger predictor of poor prognosis than immunological measures. Disease attributions may also lead to a disease oriented way of coping with a complex situation, and to a focus on bodily sensations. The recognition of the illness behaviour component is essential in understanding why, despite pharmacological treatment of the associated psychiatric disorder, neurasthenic symptoms persist (Kleinman, 1986). Kleinman also noted that only those patients improved who resolved a major family or work problem. Avoidance rather than confrontation of social stressors has been noted as a coping style in those suffering with CFS; and is associated with persistent disability (Sharpe, et al., 1992).

Moss-Morris (Moss-Morris & Petrie, 1996) in a study of functioning in CFS, found evidence to support the theory that cognitive behavioural variables were related to the presentation of CFS. Both illness representations and emotion-focused coping strategies were significantly related to functioning and psychological adjustment. Patients who believed that they had some control over CFS had more positive coping strategies, and less behavioural disengagement. In contrast those having a strong illness identity, believing the illness would last a long time and had serious consequences, were related to emotion focused coping strategies such as venting emotion, and disengaging from the stressor.

Moss-Morris also found that illness representations were more strongly associated with adjustment and well-being than coping styles. The identity component of the illness representation demonstrated the most significant associations with dysfunction, vitality and psychological adjustment. It was unclear from this study whether the disability and emotional stress resulting from the illness could determine the illness beliefs and coping responses or whether the relationship was reciprocal.

Thus personality factors could affect attention to somatic states (Brownlee, Leventhal & Balaban, 1992), they could determine interpretations of somatic states (Cioffi, 1990), and they could affect procedures for controlling illness threats and criteria for evaluating outcome. These are important aspects to consider in relation to better doctor patient understanding and agreement

about the possible psychological components of CFS. Illness perceptions may also alter presentation of symptoms to a doctors and affect the discussion surrounding them. The reception of patients' interpretations of symptoms will be discussed in the following section.

### 1.11 COMMUNICATION BETWEEN DOCTOR AND PATIENT

Perhaps one of the most fundamental elements in the acrimony that surrounds CFS is the disturbance in the doctor-patient relationship (David, et al., 1988). Leventhal's (Leventhal, Diefenbach & Leventhal, 1992) model for understanding treatment adherence sees the sufferer seeking coherence between the problem definition, the opportunity to rehearse effective actions and develop a sense of self efficacy and the criteria for evaluating outcomes. The patients' understanding of their illness as an important contributor to current medical diagnosis and treatment is beginning to be understood Kleinman (1980). The relationship between doctor and patients will not be improved unless a common understanding about the illness can be established.

Kleinman has noted that adherence to treatment in China, for neurasthenics, where there is a choice between traditional and western practitioners, appears to be high when both practitioners and patient have common representations, agree on treatment procedures and share criteria for outcome appraisals. Oriental patients interpret their symptoms in physical rather than psychological terms, attribute cause to physical rather than psychological factors and seek physiological rather than psychological treatments. Kleinman found that interpersonal inconsistency between a Chinese patient and a western psychiatrist will lead to treatment drop out.

The same finding has been noted by Scott (Scott, Deary, Pelosi, 1995) and emphasises the need for common ground for discussion between doctor and patient. Further to this Clements (Clements *et al.*, 1996) in a qualitative analysis of patients' illness beliefs, notes the importance of choice of terms used in efforts to improve doctor-patient relationships (see discussion below) and to come to a wider more enabling explanation of the illness. Unfortunately, although GPs and other health professionals were reported to have some influence on patients' illness beliefs, this was found to be remarkably little. Information put out by journalists, patient associations and



authors of self help books were found to be the main influence.

Personality-consistent illness interpretations can be encouraged and supported by an individuals social network (e.g. doctors in general practice, family members). However if a physician capitulates with the patient's denial of any affective component to CFS, this may ultimately do a disservice to the patient by preventing recognition and treatment of a problem with known safe and effective methods (Stewart, 1990). A number of suicides have been reported amongst sufferers from CFS which has led Wessely (1989) to state "The only recognised cause of death in CFS is suicide". In addition as discussed above, the belief that CFS is of purely physical aetiology often leads to chronic invalidism by reinforcing the idea that continuous rest alleviates the condition, thus leading to physical deconditioning.

Stewart is concerned with the cost to health care, social services and sickness and disability pensions by a group of people who could otherwise benefit from treatment. Manu (Manu, Matthews, Lane, Tennan, Hesselbrock, Mendola, & Affleck, 1989) has demonstrated the effectiveness of antidepressant treatment for patient's symptoms of fatigue as well as their depressive order. CBT, which focuses on broadening the patients' illness model so as to emphasise control and reversibility (Appendix 1 for a CBT formulation of CFS), is associated with clinical improvement (Sharpe, Hawton, Simkin, Surawy, Hackmann, Klimes, Peto, Warrell, & Seagroatt, 1996) .

One of the aims of the current study will be to increase knowledge of the patients' view of themselves, how they present their illness, and the meaning of their symptoms, in order to create a common understanding between physician and patient and facilitate treatment.

In the following section methodological issues and implications for the current study will be reviewed and evaluated in the light of other relevant research.

## **1.12 METHODOLOGICAL ISSUES AND IMPLICATIONS**

In order to investigate attitudes to somatic symptoms in the context of the sufferers' personality profiles, various methodologies are available. These include standard questionnaire measures of

the personality characteristics considered to be appropriate, open ended interviews or more opaque tests of attention and emotion, which can assess automatic as well as controlled processes.

### 1.12.1 The use of self report questionnaire formats

Studies using self-report questionnaire formats have encountered problems with personality groups who are described as "pseudo-healthy" (Power *et al.*, 1995). In a study of dysfunctional attitudes in depressed patients, the pseudo-healthy group despite scoring low on measures of symptomatology, scored high on measures of defensiveness and self-control. This group may be similar to that fatigued group of patients described by Shands (Shands *et al.*, 1952) and of the CFS group described by Surawy (1995) and Ray (1991), who wish to protect themselves from disruption of the integrity of their self concept, (and the resulting lowered self esteem). In doing so they avoid, either consciously or unconsciously, appearing psychologically weak or a failure.

Research into Irritable Bowel Syndrome (IBS), also considered to be in part a physiological expression of an affective disorder, Toner (Toner, Koyama, Garfinkel, Jeejeebhoy & Di Gasbarro, 1992) recorded a significantly higher score of social desirability in the IBS group than the depressed or well control group using the Marlowe Crowne Social Desirability Scale (MCSDS) (Crowne and Marlowe, 1960). The IBS group also scored significantly higher on the Lie Scale on the Eysenck Personality Inventory (L-EPI) indicating a self-schema characterised by social desirability. Elevated scores can be interpreted in at least three ways: deliberate "faking" with the intent to deceive the testers; response in terms of an ideal self-concept rather than a more realistic self-appraisal; or response in terms of an "honest" but inaccurate and un insightful self-assessment. These three interpretations share a response style that indicates defensiveness and aims to present the self in a favourable light. by endorsing socially approved items. Toner also noted that the IBS group who also fulfilled criteria for depression did not view themselves as depressed on other standard measures. Deshields (Deshields, Tait, Gfeller & Chibnall, 1995) in a study of chronic pain (also believed to have a somatising component) found that patients with higher social desirability scores emphasised physical complaints and minimised symptoms that



might suggest a psychosomatic label.

Sharpe (in press) has found high social desirability levels for CFS sufferers (mean score =18.2) compared with non patient controls (mean score=12.5) and with norms for the MC-SDS (mean score=13.72; Crowne & Marlowe, 1960). If CFS patients are similar in personality profile to IBS patients they may avoid completing questionnaires which they consider may show them to be psychologically weak. Direct questions about negative emotions may activate schemas about psychological stigma and a culture which undermines CFS as a "real" illness. This may account for Sharpe's (in press) findings that levels of perfectionism, using the self-report Perfectionism Scale (Frost, Marten, Lahart, & Rosenblate, 1990) between CFS and non-patient were similar. Questionnaires may not therefore be an efficient method of measuring personality characteristics with this patient group.

### **1.12.2 Assessment of depression using self-report questionnaires**

The use of the BDI as a rating of depression in CFS has been discussed by Ray (1991). In this scale, rates of depression are inflated by the fact that somatic symptoms which characterise CFS are also criteria for depression. The use of the Hospital Anxiety and Depression Scale (HADS) is therefore more appropriate. It was designed to avoid somatic symptoms confusing the measurement of depression (Zigmond & Snaith, 1983). However one item is still considered to reflect a characteristic symptom of CFS; "I feel as if I am slowed down." It is anticipated that this item would be endorsed by CFS sufferers as it would be understood to refer to their physical state at least partly, if not to a greater extent. It might therefore artificially raise their depression score. This must be taken into account if used in a CFS study.

### **1.12.3 Interpretations of symptoms using self-report formats**

No self-report questionnaire exists that is specifically designed to look at interpretations of symptoms in CFS. The Somatic Interpretation Questionnaire (SIQ) (Robbins 1991) used by Sharpe (in press) only includes somatic symptoms not those of mental fatigue and fatigability

which discriminate between CFS and neurological patients. Wessely and Powell (1989) used the Somatic Discomfort Questionnaire (Wittenborn & Buhler, 1979) designed to measure somatic symptoms of depression, in conjunction with a specially constructed questionnaire recording different aspects of fatigue both physical and mental. However this was a subjective measure of strength of symptoms not an attributional measure. Attributions of symptoms were measured by Wessely in a single question requiring an endorsement of one of five statements; 1. My illness is a physical one; 2. My illness is mainly physical; 3. Both physical and psychological factors are involved in my illness; 4. My illness is mainly psychological; 5. My illness is psychological in nature. Both studies used multiple choice interpretations of symptoms, limiting the responses to the imagination of the experimenters, about the possible thought processes of CFS sufferers. Further Wessely presents a relatively simple physical vs. psychological dichotomy which patients do not necessarily hold (discussed section 1.12. 5).

Clark (Clark, Salkovskis, Ost, Breitholz, Koehler, Westling, Jeavons & Gelder, submitted) provides a model for assessing sufferers' interpretations using both open-ended responses as well as experimenter provided interpretations, in a study of misinterpretation of bodily sensations in Panic Disorder.

Andrews & Brown (1993) in comparing self-report measures and interview-based measures for self-esteem, found that self-report measures were highly correlated with symptom levels, but that the interview-based measures of negative self-esteem was actually predictive of the later onset of depression. They concluded that people have little or no access to the relevant causes of their behaviour, but generate reasons that among other things may be congruent with their current mood state. They concluded that interview-based judgements by experts were superior to the individuals' own self-reports. However the questionnaire used (Rosenberg Self-Esteem Scale, 1965) measured a global factor that was symptom like (e.g. with items like "All in all I am inclined to feel that I am a failure") whereas the interview assessed self-esteem on the basis of responses to questions about specific domains such as work and parenthood. In addition Robins (Robins & Kirmayer, 1991) in exploring the causal attributions of common somatic symptoms confirmed



three dimensions; psychological, somatic and normalising. Robins established that medical and psychiatric history differentially influenced attributional style and he concluded that symptom attributional style may contribute to somatization and psychologisation of distress.

It appears that the quality of self report questionnaires can be improved by making the questions as content-specific as possible. Power *et al.* (1995) concluded that the search for cognitive vulnerability factors should focus on content-specific rather than global effects especially in the use of self-report questionnaires. However it is important to consider the medical and psychiatric history of the patient completing the questionnaire, on assessing the responses.

#### **1.12.4 Assessment of attitudes using self-report formats**

Surawy (1995) noted personality and pre-morbid lifestyle, in addition the standard methods of cognitive therapy were used to explore the patients' underlying assumptions (Beck, Rush, Shaw & Emery, 1979). The most common theme was of the high standards CFS sufferers imposed upon themselves, often with the implication that failure to meet standards would indicate failure as a person, or unacceptability to others. Second was the importance of psychological strength and of not admitting to weakness or negative feelings. Assumptions implied that self-respect and the respect of others depended on achieving high standards in most spheres of life. In addition these standards had to be achieved without sign of weakness or complaint. The anticipated consequence of not meeting standards was failure and rejection. Recollection of childhood experiences suggests that these assumptions may have arisen from an upbringing in which recognition, acceptance and affection were contingent on meeting high standards and parental expectations, and where admission of difficulty or the expression of negative emotion produced an unsympathetic response (Surawy, 1995). These assumptions are covered by standard self-report questionnaires that have good validity and reliability.

### 1.12.5 The use of qualitative methods

Qualitative methods provide an important alternative approach to questionnaire studies. This methodology has been used by Clements (Clements, Sharpe, Simkin, Borrill and Hawton, 1997 submitted) to investigate CFS patients beliefs about their illness. The approach is useful as it can complement quantitative studies in a number of ways: it can validate previous quantitative findings using a different methodology; it can aid the design of future questionnaires by providing more detailed descriptions of the phenomena under investigation; it can increase knowledge of important idiosyncrasies in the meaning that words have for patients; and hypotheses can be generated for future testing in quantitative investigations (Pope & Mays, 1995).

Clement's study is important to the current research in that it provides an insight, that only this methodology could, into the use of the word "stress" in relation to CFS sufferers ideas about the aetiology of their illness. Although antagonistic to the idea of a psychological causation, patients used the word "stress" and spontaneously reported that social stressors had played a role in the genesis of their illness (Clements, 1997). This supports previous observations from other unstructured enquiries (Ray, Weir, Cullen & Phillips, 1992; Ware, Bock, & Whelan, 1993) and implies that the simple dichotomous approach used in Wesl y's (1989) questionnaire research (reported above) is an inadequate reflection of patients' illness beliefs. The apparent contradiction between the rejection of psychogenesis and the acceptance of "stress" emphasises the significance that certain words may carry. Care in the choice of terms will be important in any quantitative studies of illness beliefs in patients with CFS; it also offers potential common ground for patients and physicians.

However the interview as a method of data collection is time consuming. If enough data is to be gathered by a single researcher to produce measurable results it would not be within the scope of this study to use such a method.



### 1.12.6 The use of experimental tasks

A third approach to data collection is to modify existing experimental tasks in a way that can assess automatic as well as controlled processes, given that the former may be less sensitive to current symptom levels than the latter (Power, 1991). These include the Emotional Stroop (Gotlib & McCann, 1984), the Self-Referent Encoding Task (SRET) ( Craik & Tulving, 1975) and the Emotional Priming Task (Power & Brewin, 1990). Wells (Wells & Matthews, 1994) has reviewed the use of the Stroop test and has expressed reservations about its validity. Evidence for these reservations and the practicalities of developing of the Stroop for the CFS patient group is beyond the scope of this study.

Toner (1990) has used the SRET to compare self-schema of CFS patients with depressed patients. Two consecutive parts to the task, (firstly rating a series of 30 depressed and 30 non-depressed content adjectives on structural, semantic and self-referent aspects; secondly making incidental recall of adjectives) demonstrated difference in self-schema between depressed patients and depressed IBS patients, measured by number and type of adjectives recalled. Given the similarities described above between IBS and CFS patients in levels of Social Desirability responses, and the difficulties this may pose for the completion of questionnaires by CFS patients; Toner's suggestion that the SRET could be modified to replicate social desirability schemas in IBS compared with depressed patients, could be used in the same way comparing CFS and depressed schemas. This could explain why patients with very similar symptoms report to infectious diseases or psychiatric specialists, because they (or their referring physician) identify their problem as organic or psychological respectively. A recognition of the differences between CFS and Depressed self-schemas might be helpful in differentiating both groups conceptually and therapeutically. The difference in self-schema may also become a useful diagnostic aid in differentiating whether depression is secondary or an intrinsic feature of CFS, given the heterogeneity of the group.

### 1.12.7 Summary of methodological approaches

Power suggests that studies of cognitive vulnerability should be pursued along all three lines of investigation (interview, questionnaire and experimental tasks) in parallel rather than seeing these as alternative or conflicting approaches. However as one purpose of the present study was to use self-report measures to explore the possible interaction of personality factors with interpretations of symptoms in CFS, the study was planned around a combination of standard questionnaires and a specifically developed questionnaire based on Clarks' model (Clark, *et al.*, submitted). This assesses sufferers' interpretations using both open-ended responses as well as experimenter provided interpretations, in order to provide a more flexible approach to the expression of patients own ideas about their illness, and to aid communication and understanding between physician and patient.

### 1.13 SUMMARY

In summary, CFS has been described as a topical and controversial illness and is currently regarded as a medically unexplained syndrome by doctors. Recently the application of the cognitive behavioural model to an understanding of its precipitation and prognosis has supported a multi-axial approach to research. Coping style and prognosis in CFS have been associated with attributional style, personality characteristics and illness perceptions, in research, and in clinical observations. The importance of good communication between doctor and patient with respect to symptom perceptions and attribution, with their possible effect on treatment pathways, has been highlighted.

The aims for this study will be focused on the above areas of interest, and will seek to provide empirical evidence for specific hypotheses relating to personality characteristics, and symptom interpretation in sufferers of CFS.



## 1.14 AIMS AND HYPOTHESES

The study has 3 aims with related hypotheses stated below.

The overall approach of the current study is to gather data about CFS sufferers in order to make a theoretical contribution to the understanding of CFS within a CBT framework. If successful the results could be used to further the treatment of CFS sufferers and to create a common understanding between physician and patient.

**AIM 1.** Aim 1 seeks to provide information about the interpretations CFS sufferers have about their symptoms, specifically with reference to psychological factors and depression, and to compare these with interpretations of similar symptoms by the control groups. In order to do this a specially designed questionnaire, based on the model used by Clark for assessing panic symptoms, will be developed as a pilot study, and subsequently used in the main study. The reliability and validity of the newly designed questionnaire will be examined, and its further development as a useful instrument for the investigation of CFS will be considered.

The following hypothesis is formulated;

### Hypothesis 1:

- H1** CFS sufferers are less likely to interpret symptoms as evidence of depression than other comparison groups.
- H0** CFS sufferers are not less likely to interpret symptoms of depression than other comparison groups.

**AIM 2.** Aim 2 will be focused on providing empirical evidence for the clinical observations of Surawy *et al.*(1995). In order to do this, the study aims to gather data about the personality profiles and attitudes of CFS sufferers, specifically; high personal standards, achievement, self-control, conscientiousness, responsibility, the consequence of failure, psychological strength,

suppression of negative emotions, pleasing others and meeting others needs. These will be measured by standard instruments. Results will be compared with two other patient groups who share similar symptoms, but have differing diagnoses of depression and multiple sclerosis, and a control group of healthy working people. In order for this aim to be investigated the following hypothesis is formulated;

### **Hypothesis 2:**

- H1** CFS sufferers are more likely than the comparison groups to have stronger beliefs about perfectionism, emotional strength, control and personal standards.
- H0** CFS sufferers are not more likely than the comparison groups to have stronger beliefs about perfectionism, emotional strength, control and personal standards.

**AIM 3.** Aim 3 will investigate the speculations of Ray (1991) and Surawy that the CFS personality profile resembles that of Beck's autonomous personality.

### **Hypothesis 3:**

- H1** CFS sufferers will score higher on measures of autonomy than either of the other three groups.
- H0** CFS sufferers will not score higher on measures of autonomy than either of the other three groups.

## **2. METHOD**

No questionnaire existed which specifically assessed interpretations of symptoms by sufferers of CFS observed in clinical work (Surawy, 1995). One of the aims of this study was to develop a questionnaire that would do this. The study was therefore planned in three parts:

1. a clinical interview with a patient who had recovered from CFS in order for the author to understand the experience of CFS, to consider the clinical findings of Surawy in more detail and to develop the new questionnaire;
2. a non-clinical pilot study of the specially created questionnaire;
3. the main study, which aimed to investigate the use of the questionnaire and other standard measures to test the hypotheses laid out in the Introduction.

Details of the Clinical Interview, the Piloting of the questionnaire and the methodology of the Main Study are described separately; as are the assessment of reliability and validity of the new questionnaire.

### **2.1 CLINICAL INTERVIEW**

#### **2.1.1 PARTICIPANT**

The responsible clinician gained permission from a clinical patient, who had recovered from CFS after a course of CBT, to be interviewed as part of follow up from treatment. The interview participant was a 42-year old female who had suffered from CFS for 2 years and had recovered in the last year.

#### **2.1.2 DESIGN**

An interview with the recovered participant based on CBT follow-up procedure.



### 2.1.3 MEASURE

The clinical interview was unstructured and assessed:

- (i) Symptoms of CFS.
- (ii) A comparison with the symptoms of post-natal depression, which the participant had also experienced. The question of whether the participant believed CFS was depression, and the implications for her if this was true.
- (iii) The course of the illness.
- (iv) The cognitions and emotions experienced in relation to the symptoms.
- (v) The change in cognitions during CBT.
- (vi) The participant's account of the recovery process and the change in attitudes towards life style resulting from recovery.

### 2.1.4 PROCEDURE

**Ethical approval:** The interview was part of a clinical follow-up to therapy, and was supervised by the responsible clinician, ethical approval was therefore not sought.

The interview was approximately an hour and a half long and was carried out by the researcher and the responsible clinician.

### 2.1.5 RESULTS

Ideas expressed by the participant corresponded closely to those observed by Surawy *et al.* (1996), the participant had an action oriented pre-morbid lifestyle involving helping others as a high priority. She described herself as highly conscientiousness and perfectionistic, with high personal standards. Attributions of illness also corresponded closely to those findings by Clements *et al.* (1996) discussed in the Introduction. Depression was rejected as an explanation of the illness, but it was conceded that stress could have been a causal factor.

Information gained from the initial interview aided the authors understanding of the manifestation of CFS, and indicated specific symptoms and attitudes to be used in both the

questionnaires.

## **2.2 PILOT STUDY**

The aim of the pilot study was to develop the design and individual items of the Interpretations of Symptoms in CFS measure (IS-CFS) for validity and reliability. Items were based on the initial patient interview and the clinical observations of Surawy. Answers from participants would be used as measures of validity and reliability.

### **2.2.1 PILOT STUDY PARTICIPANTS**

**Participants:** Twenty first and second year clinical psychology students were approached by letter (Appendix 2) to take part in piloting the two questionnaires.

**Criteria for inclusion:** Participants completing the questionnaires needed to have been physically and emotionally well enough in the last year to continue with their studies. This was a criteria which they were required to judge for themselves.

### **2.2.2 PILOT STUDY DESIGN**

Design was a within subjects comparison design.

### **2.2.3 PILOT STUDY MEASURES**

The Interpretations of symptoms questionnaire (IS-CFS). Demographic data was collected from the participants including age and sex. In addition participants were asked to state the time taken to complete the questionnaire, any concentration or memory problems experienced during completion, and to comment on the content of the questions especially if any questions offended or upset them.

#### **2.2.3.1 IS-CFS questionnaire**

Questionnaire format was based on a model developed by Clark *et al.*, (submitted) for Assessing



Misinterpretation of Body Sensations in Panic Disorder (Appendix 3); and the findings of Robbins (Robbins & Kirmayer, 1991) who established that medical and psychiatric history differentially influenced attributional style, and that symptom attributional style may contribute to somatization and psychologisation of distress.

The format of the IS-CFS (Appendix 4) asked 12 open ended questions (producing "open ended" answers) about the aetiology of symptoms typical of CFS, but which are also found in depression and multiple sclerosis. These questions were followed by experimenter generated alternate explanations (producing "closed answers") which participants were asked to rank in the order that the explanations might occur to them. These alternative explanations were created to represent either; a negative emotional state, a positive emotional state, a physical problem, or a normalising explanation for the given event or symptom.

The format of the IS-CFS was designed in order that the negative emotional/cognitive explanation of the 12 symptoms could be tracked. This would be done both by the categorisation of the answer to the open ended question by two raters; and by the ranking of the negative answer in relation to the other 2 or 3 experimenter generated explanations, for each of the 12 symptoms. The results from this measure would be used to test Hypothesis 1; that CFS sufferers are less likely to interpret symptoms as evidence of depression than other comparison groups.

#### **2.2.4 PILOT STUDY PROCEDURE**

The questionnaires were piloted on non-clinical population with the full knowledge and consent of the participants as to the nature of the research. The voluntary nature of the exercise was emphasised. Ethical approval was not required as the pilot was using a non-clinical population.

Participants in the questionnaire study were contacted by explanatory letter, followed by the questionnaires. The author was available to answer any questions about the study. The questionnaires were redistributed 4 to 6 weeks later for re-test. At re-test participants were also asked to rate the experimenter generated explanations in the Interpretations questionnaire, as one of the four explanations, described above, or as unclassifiable. To ascertain whether any



concentration or memory problems could have significant effects on the responses to questionnaires, participants were asked to time the completion of each questionnaire in the package and to rate concentration and memory problems on completion. Tests of reliability and validity were carried out on individual items.

### **2.2.5 PILOT STUDY RESULTS**

Results of the IS-CFS pilot showed no items were considered offensive or upsetting, no participants experienced memory or concentration problems during completion. This on average took 6 minutes.

#### **2.2.5.1 Demographic data**

Participants were all clinical psychology trainees in the first two years of training, 8 men and 12 women. All were aged in their 20s except one female in her 30s.

#### **2.2.5.2 Response Rate**

Response rate for both questionnaires was 100% (20 returns) for the initial distribution of questionnaires and 95% (19 returns) for the re-test.

#### **2.2.5.3 IS-CFS results**

**Inter-rater reliability:** Open-ended responses to each of the 12 items in the IS-CFS provided a range of cognitions from each of the 20 participants. All responses were rated by the researcher and an independent judge, who allocated them to one of 4 categories; a physical explanation, a normalising explanation, a negative emotional explanation or a positive emotional explanation. In addition there was a category for "any other" unspecified explanation. Overall reliability was calculated using Cohens Kappa. Table 3 summarises Kappa Coefficients for inter-rater reliability. This indicated a moderate to perfect agreement between judges (Landis & Koch, 1977).

**Table 3** :IS-CFS<sup>a</sup> Kappa Coefficients for inter-rater reliability on open ended response, N=20.

Question		Kappa	Strength of Agreement <sup>b</sup>
1.	You notice that you cannot concentrate. Why?	0.918	almost perfect
2.	You have abdominal pain and diarrhoea. Why?	1.000	perfect
3.	You have been waking in the early hours of the morning. Why?	0.600	moderate
4.	You notice your memory is failing you Why?	0.855	almost perfect
5.	You are experiencing headaches. Why?	0.756	substantial
6.	You notice you have no enthusiasm for life Why?	0.931	almost perfect
7.	Your heart is pounding. Why?	.858	substantial
8.	You notice you are feeling more tired than usual. Why?	.764	substantial
9.	You have recently lost weight without trying. Why?	.807	substantial
10.	You notice you are feeling irritable and anxious in the evenings. Why?	.924	almost perfect
11.	You seem to be constantly jumpy and alert. Why?	1.000	perfect
12.	You find you are having to urinate more frequently throughout the day. Why?	0.829	almost perfect

<sup>a</sup> IS-CFS Interpretations of symptoms in chronic fatigue syndrome; <sup>b</sup>Interpreted according to Landis and Koch (1977).

**2.2.5.4 IS-CFS Test-re-test reliability:**

Overall reliability was calculated using Cohens Kappa. Table 4 summarises Kappa Coefficients for inter-rater reliability. This indicated a slight to perfect agreement over time (Landis & Koch, 1977).

**Table 4** *IS-CFS<sup>a</sup> Kappa Coefficients for test re-test reliability on open ended responses, N=20.*

Question	Kappa	Strength of Agreement <sup>b</sup>
1. You notice that you cannot concentrate. Why?	.135	slight
2. You have abdominal pain and diarrhoea. Why?	.829	almost perfect
3. You have been waking in the early hours of the morning. Why?	.483	moderate
4. You notice your memory is failing you. Why?	.423	moderate
5. You are experiencing headaches. Why?	.663	substantial
6. You notice you have no enthusiasm for life. Why?	1.000	perfect
7. Your heart is pounding. Why?	.584	moderate
8. You notice you are feeling more tired than usual. Why?	.337	fair
9. You have recently lost weight without trying. Why?	.5122	slight
10. You notice you are feeling irritable and anxious in the evenings. Why?	.508	moderate
11. You seem to be constantly jumpy and alert. Why?	.374	fair
12. You find you are having to urinate more frequently throughout the day. Why?	.222	fair

<sup>a</sup> IS-CFS Interpretations of symptoms in chronic fatigue syndrome; <sup>b</sup>Interpreted according to Landis and Koch (1977).

#### 2.2.5.5. IS-CFS Validity of categories for experimenter generated explanations

On re-test all 19 participants categorised the experimenter provided explanations for each of the 12 items. The four categories were; a physical explanation, a normalising explanation, a negative emotion/cognition explanation or a positive emotion/cognition explanation, as above, with the additional "any other" unspecified category. It was presumed that the IS-CFS would be answered as if by a well population, and endorsement of the negative emotional explanation would therefore not be expected to any great extent by this population.



Overall participants correctly categorised 91% of the physical explanation , 89.5% of the normalising explanation, 99.1% of the negative emotion/cognition explanation and 96.8% of the positive emotion/cognition explanation; 1.8% of the total number of possible answers were categorised incorrectly as "any other". The number of correct responses for individual item explanations ranged from 12/19 (63%) to 19/19 (100%). Whilst the negative and positive emotion/cognition explanations seemed easy to identify for the participants, the normalising explanation was most commonly confused with the physical explanation.

## **2.2.6 MODIFICATION OF QUESTIONNAIRES**

The IS-CFS questionnaire was modified as a result of the pilot study.

### **2.2.6.1. Modification of the IS-CFS**

Modification was made to the items of the IS-CFS in order to fit precise definitions which were also more appropriate for the CFS patient populations being studied (see description of IS-CFS in the main study).

Two researchers with a knowledge of CFS checked the questionnaire package for clarity and accuracy. The final versions of the IS-CFS was used in the Main Study.

## **2.2 MAIN STUDY**

### **2.2.1 PARTICIPANTS**

Four groups of participants were recruited for the main study. Chronic Fatigue patients, Multiple sclerosis patients, depressed patients and a group of people who had been physically and mentally well enough to work in the last year, to provide as near a "normal" group of controls as possible.

No other study has used this combination of subject groups. Wessely and Powell (1989) studied a combination of CFS, neuromuscular and depressed patients, and Trigwell (Trigwell, Hatcher, Johnson, Stanley & House, 1995) compared patients with CFS and Multiple



Sclerosis (MS). The three patients groups share similar symptoms such as physical and mental fatigue, pain, concentration and memory problems. In addition fatigue in MS is independent of neurological deficits and does not correlate well with depression. It is also similar to CFS in tending towards a relapsing and remitting, uncertain course and often being characterised by non-specific symptoms.

**Chronic Fatigue (CFS) Patients:** were recruited from a study already in place in Oxford (Clements, 1996). This study group had originally been recruited by contacting consecutive referrals from general practice to a medical infectious disease clinic. All patients were assessed by a physician, and a psychiatrist in order to determine eligibility for inclusion. Patients had to be aged between 18 and 50 years and meet the 1991 criteria for CFS and the revised CDC criteria 1994 when applied retrospectively (see Introduction).

**Depressed (DEP) Patients:** were recruited from a psychiatric clinic run from a G.P. surgery, a psychiatric outpatients clinic, two psychiatric in-patient wards, a psychology outpatients clinic and a G.P. surgery. Only those patients meeting DSMIV criteria for unipolar depression, scoring above 8 on the depression sub scale of the Hospital Anxiety and Depression Scale, were selected.

**Exclusion criteria** for depressed patients included; those with a major symptom of fatigue; those who's level of concentration was too low to complete a questionnaire alone; those receiving cognitive therapy; those who's level of literacy precluded responding by questionnaire; those experiencing a depressive cycle which was part of a bi-polar picture; those with psychosis as a complicating factor; those well above the age range 18-50 years.

Patients were approached either in person or by letter after first seeking ethical approval and the responsible clinicians consent.

**Multiple Sclerosis (MS) Patients:** were recruited from a study in Oxford investigating the prevention of physical relapse by Beta Interferon. Participants from this study had originally been contacted through G.P. surgeries and were aged between 18 and 55 years. Patients were at two stages of the illness; either a relapsing remitting stage or a secondary

progressive stage. The Oxford study had noted mood level was unaffected by length of illness, but was effected by whether or not the illness had been accepted, this varied amongst those responding to the current study. Patients' mood level was unaffected by Beta Interferon, however some patients were prescribed from 10 to 25 ml. grams of amytriptaline per day for bladder control, and this had some effect on raising mood.

**Exclusion criteria** for MS patients included; those whose cognitive level precluded completion of questionnaires; and those whose physical symptoms precluded completion of questionnaires without help.

**Working population group:** were recruited from staff in work places in Oxfordshire; these included a school, a hospital outpatients department, a solicitors office, a garage, a social services department, a glass works, and a university department. The group comprised people in full time or part time work.

**Exclusion criteria** included those who had not been physically or emotionally well in the last year to a significant extent, (It was left to the participant to judge this for themselves, following guidelines set out in an explanatory letter or were outside the age range 18-50 years.

## 2.2.2 DESIGN

Design was a groups comparison study, using the Interpretations of Symptoms (IS-CFS) questionnaires specially created for the study; the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983); the Dysfunctional Attitudes Scale 24 (DAS24; Power *et al.*, 1994); the Multidimensional Perfectionism Scale (MPS; Frost *et al.*, 1990) and the Personal Style Inventory (PSI; Robins *et al.*, 1994).

## 2.2.3 MEASURES

### 2.2.3.1 Interpretations of symptoms questionnaire (IS-CFS)

IS-CFS remained as a 12 item scale with some items adapted after the Initial Study (Appendix 5). The 12 items described symptoms common to CFS, MS and Depression and asked for an



explanation for these (for example "You have abdominal pain and diarrhoea. Why?"). On turning the page participants were asked to rate experimenter generated explanations in the order they would be most likely to occur to them even if these explanations did not match their previous open ended explanation. Eight items were given 3 experimenter generated alternatives corresponding to a negative emotional/cognitive explanation, an illness or infection reason, and a normal bodily reaction to the environment or stress put upon the body. In addition, 4 items were given a positive emotional/cognitive explanation. These criteria were adapted from the criteria originally devised in the Initial Study and corresponded more closely to Robbins' (Robbins & Kirmayer, 1991) three dimensions of causal attributions of common somatic symptoms, defined as; psychological, somatic and normalising (for example "You have abdominal pain and diarrhoea. Why? a. You are worried and anxious about problems. b. You have a stomach bug. c. The natural balance of your gut has been put out by something you have eaten, it can easily be restored").

The design of the instrument was intended to categorise participants responses into Robbins three dimensions and to be able to show a difference in Interpretation of symptoms between participants groups. The questionnaire was prefaced by an example of a completed item.

2.2.3.2 Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) The HADS is a 14 item self-report scale developed to measure anxiety and depression amongst medical outpatients (Appendix 6). Total scores for each sub scale are obtained by summing the responses to individual items, the possible range is 0-21 for each sub scale. Results can be interpreted by scoring bands (Appendix 7). Zigmond reports reliability measured by Cronbachs  $\alpha=0.93$  for medical patients aged 16-65 years.

In the current study the use of the Hospital Anxiety and Depression Scale (HADS) was more appropriate than an instrument such as the Beck Depression Inventory, as the design avoided somatic symptoms confusing the measurement of depression. However one item "I feel as if I am slowed down" might have been highly endorsed by CFS sufferers, as it might have been understood to refer to their physical state at least partly, if not to a greater extent. It might

therefore have artificially raise their depression score. Depression scores were therefore calculated both with and without this item.

**2.2.3.3 Dysfunctional Attitudes Scale 24 Item (DAS24; Power *et al.*, 1994)** The DAS-24 (Appendix 8) is an instrument used to identify negative dysfunctional attitudes which contribute to cognitive vulnerability to emotional disorders, and is developed from the original 100-item form (Weissman & Beck, 1978) by Power *et al.*, (1994). The 24-item form uses three sub scales measuring attitudes to Achievement, Dependency and Self-Control and which indicate a rate of depression-specific vulnerability factors. It is scored on a scale of 24 to 168, with a higher score indicating higher level of dysfunctional attitudes. The norms for normal adult population N=142, for Achievement sub scale mean=21.67, sd=9.38, for Dependency sub scale mean=27.48, sd=9.61, for Self-Control sub scale mean=26.57 sd=7.91, for total score mean=75.71, sd=20.76.

Power *et al.*, report internal consistencies of sub scales (Cronbach's alpha) of 0.847, 0.737 and 0.681 for the Achievement, Dependency and Self-Control scales, respectively. The Pearson *r* intercorrelations for the sub scales were Achievement-Dependency, 0.570, Achievement-Self-Control, 0.506, and Dependency-Self-Control, 0.248, all of which were significant at  $p>0.001$  with a sample size of N=294.

**2.2.3.4 Multidimensional Perfectionism Scale (MPS; Frost *et al.*, 1990)** The MPS is a 35 item instrument which measures aspects of Perfectionism (Appendix 9). These include; excessive concern over making mistakes, high personal standards, the perception of high parental expectations, the perception of high parental criticism, the doubting of the quality of one's actions and a preference for order and organisation. Perfectionism is hypothesised to play a major role in a wide variety of psychopathologies. Perfectionists also tend to have higher levels of Self-Critical Depression but not Dependency Depression (Frost *et al.*, 1990). The MPS is scored on a scale from 0-210 with a higher score indicating a higher level of perfectionism.

Frost reports the coefficients of internal consistency (Cronbach's alpha) as .77 doubts



about actions; .83 personal standards; .84 parental criticism and parental expectations; .88 concern over mistakes; and .93 organisation; with an internal reliability of the overall perfectionism score  $\alpha=.90$ . Frost *et al.*, reports the MPS is highly correlated with other scales of perfectionism.  $N=178$ . Norms are not available for this scale.

**2.2.3.5 The Personal Style Inventory (PSI; Robins *et al.*, 1994)** The PSI is a 48 item instrument which measures aspects of sociotropy and autonomy, constructs which have been associated with vulnerability to depression (Appendix 10). Two groups of sub scales have been identified: the sociotropic sub scale includes, concern about what others might think, dependency, and pleasing others; the autonomy sub scale includes, perfectionism/self criticism, need for control and defensive separation. The items are scored from 1-6 corresponding to labels "strongly disagree" to "strongly agree". Scoring is on a scale from 24-144 for the each sub scale group, with higher scores indicating higher levels of sociotropy or autonomy.

The norms for normal adult population  $N=411$ , Sociotropy sub scale mean=95.8  $sd=15.9$ , autonomy subscale mean=82.6,  $sd=15.1$ . Test-retest stabilities were .80 for sociotropy and .70 for autonomy, and both the sub scales have a significant negative correlation with social desirability responding compared with the Marlowe-Crowne (1960) social desirability scale.

#### **2.2.3.6 Background Information**

This consisted of basic demographic data (age, sex, ethnic origin, marital status), educational qualification, current occupation, occupation prior to illness, current occupation status, and length of illness (Appendix 11). Questionnaires were answered anonymously and were therefore colour co-ordinated in order to distinguish the patient group to which they belonged. The Information sheet was designed by the author based on a similar model used by a previous study with the CFS group (Clements, 1996). The authors contact telephone number was included in the Information sheet in order for any questions to be answered. A standard consent form was included where appropriate (Appendix 12).

## 2.2.4 PROCEDURE

**2.2.4.1 Ethical approval:** Regional Ethics Committee approval was sought and received (Appendix 13) initially for a design using the specially created IS-CFS, the Beck Depression Inventory (Beck, 1961), the Self Evaluation Questionnaire (Spielberger, 1977), the Personal Style Inventory (PSI; Robins *et al.*, 1994), Dysfunctional Attitudes Scale 24 Item (DAS24; Power *et al.*, 1994), and the Multidimensional Perfectionism Scale (MPS; Frost *et al.*, 1990); for use with only the three patient groups.

Later amendments were given ethical approval . These included the use of the HADS instead of the combination of the BDI and the Self Evaluation Questionnaire. Permission was also gained for the use of a control group of working population, and for the extension of recruitment for depressed patients through G.P. surgeries.

### 2.2.4.2 Piloting the questionnaire package

The completed revised questionnaire package was piloted in order to ascertain the face validity of the revised IS-CFS, and to time the completion of the package. A participant who was suffering from CFS completed the package and commented on the contents and presentation. Items were judged to be relevant to the concerns of a CFS sufferer. The whole questionnaire package was judged to be manageable and clear to someone with CFS.

**2.2.4.3 Recruitment:** The names of potentially suitable patients were obtained from the relevant hospital specialist after their agreement had been sought. G.P.s were then notified in writing (Appendix 14) to ensure there was no objection to the patient being included.

Initial CFS participant recruitment was by phone. The first thirty subjects who were contacted by phone by the author of the above research (Clements, 1996), and responded positively to an invitation to take part, were sent a questionnaire by post. They were asked to repeat completion of the IS-CFS, 4-6 weeks from the return of the first questionnaire. In order to



protect their anonymity from the researcher of the current study, the above researcher (Clements) screened the returned questionnaires, and made 1 follow up phone call if the first questionnaires were not returned within 3 weeks. No follow up was made for the retest questionnaire.

Initial recruitment of depressed patients was made through the responsible clinician, followed by a letter from the author or by a short meeting with the author. Those who agreed to take part were sent a questionnaire by post. Anonymity was guaranteed, there were therefore no follow up phone calls.

Initial recruitment of MS patients was through the researcher on the Oxford Beta Interferon study as part of follow up interviews. Again, as anonymity was guaranteed the researcher on the Beta Interferon study distributed the questionnaires and made 1 follow up phone call if the questionnaire was not returned within 3 weeks.

Initial recruitment of working control group was through management of the workplaces, permission was gained before members of staff were contacted. Anonymity was guaranteed, managers distributed questionnaires following a visit from the researcher to explain the study.

**2.2.4.4 Inter-rater Reliability:** Inter-rater reliability was assessed by an independent rater on 30% of the returned questionnaires from each participating group, following the procedure used by (Clark submitted)Clark (submitted).

**2.2.4.5 Test Re-test Reliability:** This was assessed by re-distributing the IS-CFS to the CFS group (described above).



### **3. RESULTS**

#### **3.0 MAIN STUDY**

**3.1 Overview of results section:** The main aim of the current study is to make a theoretical contribution to the understanding of CFS within a CBT framework. Following discussion of demographic details of the participating groups, and levels of depression and anxiety, demonstration of reliability and validity factors associated with the development of the IS-CFS will be presented. Data will then be considered as it relates to the core aims and hypotheses.

#### **3.2 Response Rates**

Details of response rates are presented in Table 5. A total of 147 questionnaires were sent to potential participants, with a total return rate of 94 (63.9% response rate) 40 were male and 54 female. Of those sent out to each group, 63% of potential participants from the CFS group replied (7 male, 12 female), 56% from the potential depressed group (13 male, 15 female), 73% from the potential MS group (7 male, 12 female), and 68% of the potential working control group (13 male, 15 female). Refusal rates were roughly equal between male and female in each group. Ten of the Depressed sample who completed the questionnaires were found to score 7 or below (the cut-off point for borderline clinical significance) on the Depression sub scale (Snaith & Zigmond, 1994). They were therefore excluded from the study. Those who remained in the Depressed group numbered 18; 7 male and 11 female.

**Table 5.** *Table of response rates to questionnaire packages with covering letter.*

	Total number questionnaires sent(%)	Number of completed responses (% of total sent)	Number of responses un-retuned or declined to complete (% of total sent)
<b>Test</b>			
CFS <sup>a</sup> total	30 (100%)	19 (63%)	11 (37%)
CFS male	13 (43%)	7 (23%)	6 (20%)
CFS female	17 (57%)	12 (40%)	5 (17%)
DEP <sup>b</sup> total	50 (100%)	28 (56%)	22 (44%)
DEP male	23 (46%)	13 (26%)	10 (20%)
DEP female	27 (54%)	15 (30%)	12 (24%)
MS <sup>c</sup> total	26 (100%)	19 (73%)	7 (27%)
MS male	n/k	7 (27%)	n/k
MS female	n/k	12 (46%)	n/k
WK <sup>d</sup> total	41 (100%)	28 (68%)	13 (32%)
WK male	19 (46%)	13 (32%)	6 (15%)
WK female	22 (54%)	15 (36%)	7 (17%)
<b>Total</b>	<b>147 (100%)</b>	<b>94 (63.9%)</b>	<b>53 (36.1%)</b>

<sup>a</sup>Chronic Fatigue Syndrome Group <sup>b</sup>Depressed Group <sup>c</sup>Multiple Sclerosis Group <sup>d</sup>Working Group

A total of 19 re-test questionnaire packages were sent out to the CFS group, with a total return rate of 15 (79% response rate). All 4 refusals at re-test were from women (time of re-test was during school holidays). These are presented in table 6.

**Table 6.** *Response Rates to Re-test Questionnaire Packages with covering letter.*

	Total number re-test questionnaires sent(%)	Number of completed responses (% of total re-test sent)	Number of responses un-retuned or declined to complete (% of total re-test sent)
<b>Re-test</b>			
CFS <sup>a</sup> total	19 (100%)	15 (79%)	4 (21%)
CFS male	7 (37%)	7 (37%)	0 (0%)
CFS female	12 (63%)	8 (42%)	4 (21%)

<sup>a</sup>Chronic Fatigue Syndrome Group

**3.3 Demographic Data** for the sample is presented in Table 7

Where comparison of means were required one-way analysis of variance were conducted to detect differences between groups on the demographic data. The non-parametric Kruscal-Wallis one-way analysis of variance was used where between group variances were unequal (at  $p < .05$ ) using Levene's test for equality of variances). Post hoc tests were carried out to locate the source of any significant differences found. Bonferroni tests ( $p < .05$ ) and Mann-Whitney U - Wilcoxon Rank Sum W tests ( $p < .05$ ) were used respectively.



**Table 7** *Demographic data for sample in main study.*

	CFS <sup>a</sup> (N=19)	DEP <sup>b</sup> (N=18)	MS <sup>c</sup> (N=19)	WK <sup>d</sup> (N=28)
<b>Participant Characteristics</b>				
Mean (SD) <sup>e</sup> age in years	40.7 (7.2)	41.8 (11.5)	41.4 (6.5)	37.1 (7.8)
Female % of total (No.)	14.2% (12)	13% (11)	14.2% (12)	17.8% (15)
Male % of total (No.)	8.3% (7)	8.3% (7)	8.3% (7)	15.4% (13)
Single % of total (No.)	3.6% (3)	9.6% (8)	4.8% (4)	6% (5)
Married/cohabiting % of total (No.)	16.8% (14)	6% (5)	16.8% (14)	22.8% (19)
Separated/divorced % of total (No.)	1.2% (1)	6% (5)	1.2% (1)	4.76% (4)
Education beyond 18 years % of total (No.)	15.6% (13)	10.8% (9)	8.4% (7)	27.7% (23)
Unable to work or study % of total (No.)	7.2% (6)	4.8% (4)	2.4% (2)	n/a
Full time work % of total (No.)	3.6% (3)	3.6% (3)	8.4% (7)	28.9% (24)
Part time work % of total (No.)	3.6% (3)	1.2% (1)	4.8% (4)	3.6% (3)
Social Class 1 & 2 % of total (No.)	15.5% (13)	15.5% (13)	8.3% (7)	27.4% (23)
Social Class 3, 4 & 5 of total (No.)	7.2% (6)	5.9% (5)	14.3% (12)	5.9% (5)

<sup>a</sup>Chronic Fatigue Syndrome Group; <sup>b</sup>Depressed Group; <sup>c</sup>Multiple Sclerosis Group; <sup>d</sup>Working Group; <sup>e</sup>Standard Deviation.

Results showed that of the 84 participants in the study the 4 groups did not differ significantly in mean age. Men were 40% of respondents and women 60%. A higher number of the depressed sample were single than the other groups. The divorced/separated rate for the depressed group was closer to that of the working group, which were both higher than the MS and CFS groups. The MS group had the lowest level of education and a higher percentage in social class 3,4,and 5 than the other groups. The CFS group contained the highest percentage of participants unable to work or study, and shared the lowest percentage of participants in full time work with the depressed group.

Table 8 presents illness characteristics of the 4 groups. Mean duration of illness is lower in the CFS group. The CFS group had significantly more time off work due to illness than the depressed group, (the MS group comprised only 1 participant in that particular category ).

**Table 8** *Illness characteristics of participant groups*

	CFS	DEPRESSED	MS	WORKING
	(N=19)	(N=18)	(N=19)	(N=28)
<hr/>				
<b>Illness characteristics</b>				
Mean duration of illness in months (SD) <sup>d</sup>	65.1 (24.1)	117 (135.9)	117 (70.2)	n/a
Mean time off work in months (SD)	55.2 <sup>a</sup> (20.3)	22.2 <sup>b</sup> (14.49)	192 <sup>c</sup> (0)	n/a
Time off work % of total (No.):				
1 year and under	0% (0)	2.38 (2)	0% (0)	n/a
13 months to 3 years	3.57% (3)	1.19% (1)	0% (0)	n/a
37 months and above	4.76% (4)	0% (0)	1.19% (1)	n/a

<sup>a b c</sup> Within each measure means with different superscripts (including lack of superscript) are significantly different from each other. <sup>d</sup>Standard Deviation.

Table 9 presents total time taken to complete the questionnaire package and participants scores for memory problems and concentration problems throughout. There was no significant difference in mean time between groups for completing the questionnaires. However mean scores for concentration problems and memory problems for the patient groups were significantly different from the working group. The depressed and CFS samples experienced significantly more problems than the MS group.

**Table 9** *Completion of questionnaires by participant groups*

	CFS	DEPRESSED	MS	WORKING
	(N=19)	(N=18)	(N=19)	(N=28)
<b>Completion of Questionnaires</b>				
Total time taken in minutes, means (SD) <sup>d</sup>	36.5(14.8)	34.7 (19.1)	40.6 (14.7)	31.8 (9.6)
Concentration problems means (scale 1-10)	2.26 <sup>a</sup> (2.5)	2.3 <sup>a</sup> (2.3)	1.26 <sup>ab</sup> (1.99)	0.64 <sup>b</sup> (1.19)
Memory problems means (scale 1-10)	1.78 <sup>a</sup> (2.27)	2.0 <sup>a</sup> (2.65)	0.42 <sup>b</sup> (1.21)	0.32 <sup>b</sup> (0.98)

<sup>a b c</sup> Within each measure means with different superscripts (including lack of superscript) are significantly different from each other. <sup>d</sup>Standard Deviation.

**3.4 Hospital Anxiety and Depression Scale**

After removal of the 10 participants from the depressed group who scored lower than 7 on the depression subscale in the HADS, mean scores for depression were all above the cut off point of 7, in only in the depressed group. The MS and CFS group mean scores were not significantly different from each other, but were significantly higher than the working group. However these results included the item "I feel as if I am slowed down." When this was removed, depression rates dropped in all groups but left the relationships between mean scores the same, with the depressed group still scoring above the cut off point for depression. Anxiety means showed the CFS group scoring the lowest, not significantly different from the working group, but significantly different from the MS group. The depressed group again scored over the cut off point of 7, for clinical levels of anxiety.



**Table 10**      *Data from Hospital Anxiety and Depression scales (HADS)<sup>a</sup>*

<u>Groups</u>	CFS <sup>b</sup> (n=19)	DEP <sup>c</sup> (n=18)	MS <sup>d</sup> (n=19)	WK <sup>e</sup> (n=28)
Depression means (SD) <sup>f</sup>	5.36 <sup>a</sup> (3.75)	13.6(2.85)	6.21 <sup>a</sup> (2.99)	2.29 <sup>b</sup> (1.69)
Depression means (SD) minus q. 8. <sup>g</sup>	3.47 <sup>a</sup> (3.23)	11.39(2.63)	3.95 <sup>a</sup> (2.5)	1.39 <sup>b</sup> (1.52)
Anxiety means (SD)	4.47 <sup>a</sup> (2.95)	13.28(3.06)	7.89 <sup>b</sup> (3.63)	6.14 <sup>ab</sup> (3.69)

<sup>a</sup>Cut-off for borderline significance greater than 7 for each sub scale (Snaith and Zigmond, 1994); <sup>b</sup>Chronic Fatigue Syndrome Group; <sup>c</sup>Depressed Group; <sup>d</sup>Multiple Sclerosis Group; <sup>e</sup>Working Group; <sup>f</sup>Standard Deviation; <sup>g</sup>"I feel as if I am slowed down"; <sup>ab</sup>Within each measure means with different superscripts (including lack of superscript) are significantly different from each other.

**3.5            Aim 1. ESTABLISHMENT OF THE PSYCHOMETRIC PROPERTIES OF THE IS-CFS**

**3.5.1        IS-CFS inter-rater reliability for open ended responses**

An independent rater allocated answers (on 30% of the returned questionnaires from each participating group) to one of five categories; negative emotional/cognitive explanation; a positive emotional/cognitive explanation; an illness reason, disease, or malfunction of the body; a normal bodily reaction to the environment or to stress put upon the body (not the mind); and an unclassifiable category. This followed the procedure used by Clark (submitted), (Appendix 15 for category criteria).

Table 11 summarises Kappa Coefficients for inter-rater reliability, between the independent rater and the researcher.

**Table 11** *Kappa Coefficients for inter-rater reliability on open ended responses to Interpretations questions, N=29.*

Question	Kappa	Strength of Agreement <sup>a</sup>
1. You have tense muscles. Why?	0.9384	almost perfect
2. You notice that you cannot concentrate. Why?	1.0000	perfect
3. You have abdominal pain and diarrhoea. Why?	0.9383	almost perfect
4. You have recently lost weight without trying. Why?	0.9441	almost perfect
5. You have been waking in the early hours of the morning. Why?	0.8586	almost perfect
6. You are having difficulty focusing your attention. Why?	0.9398	perfect
7. You find you are having to urinate more frequently throughout the day. Why?	1.0000	perfect
8. You are feeling tired. Why?	1.0000	perfect
9. Your heart is pounding. Why?	1.0000	perfect
10. You are lacking energy. Why?	1.0000	perfect
11. You are experiencing headaches. Why?	0.9323	almost perfect
12. You are feeling on edge. Why?	0.7878	substantial

<sup>a</sup> Interpreted according to Landis and Koch (1977).

Inter-rater reliability showed 100% ratings of categories of responses carried substantial to perfect agreement. Unclassifiable answers were 2.5% of the responses. Results suggest that categorisation of open ended answers is straight forward given the criteria categories (Appendix 15).

**Test re-test reliability of IS-CFS** This was assessed by re-distributing the IS-CFS to the CFS group (described above). Table 12 summarises these results below.

**Table 12** *Kappa Coefficients for test re-test reliability on open ended responses to Interpretations questions, N=15.*

Question	Kappa	Strength of Agreement <sup>a</sup>
1. You have tense muscles. Why?	.635	substantial
2. You notice that you cannot concentrate. Why?	.580	moderate
3. You have abdominal pain and diarrhoea. Why?	.857	almost perfect
4. You have recently lost weight without trying. Why?	.478	moderate
5. You have been waking in the early hours of the morning. Why?	.757	substantial
6. You are having difficulty focusing your attention. Why?	.556	moderate
7. You find you are having to urinate more frequently throughout the day. Why?	.152	slight
8. You are feeling tired. Why?	1.000	perfect
9. Your heart is pounding. Why?	.873	almost perfect
10. You are lacking energy. Why?	.435	moderate
11. You are experiencing headaches. Why?	.724	substantial
12. You are feeling on edge. Why?	.257	fair

<sup>a</sup> Interpreted according to Landis and Koch (1977).

Test re-test reliability showed ratings of categories of open ended responses carried slight to perfect agreement. Results suggest that open ended answers from CFS sufferers, elicited by these particular questions, will vary in stability over time, and that some will vary more than others. Significance values were 16.6% slight to fair, 33.3% moderate and 50% substantial to perfect. Test re-test reliability was also calculated for the ranking of the negative mood answer from the experimenter generated closed ended responses. Table 13 summarises these results.



**Table 13** *Kappa Coefficients for test re-test reliability on ranking of the negative mood/cognitions explanation in the closed ended experimenter generated responses to the IS-CFS questions, N=15.*

Question	Kappa	Strength of Agreement <sup>a</sup>
1. You have tense muscles. Why?	.346	fair
2. You notice that you cannot concentrate. Why?	.401	fair
3. You have abdominal pain and diarrhoea. Why?	-.129	poor
4. You have recently lost weight without trying. Why?	.170	slight
5. You have been waking in the early hours of the morning. Why?	.689	substantial
6. You are having difficulty focusing your attention. Why?	.485	moderate
7. You find you are having to urinate more frequently throughout the day. Why?	.386	fair
8. You are feeling tired. Why?	.517	moderate
9. Your heart is pounding. Why?	.350	fair
10. You are lacking energy. Why?	.067	slight
11. You are experiencing headaches. Why?	.355	fair
12. You are feeling on edge. Why?	.176	slight

<sup>a</sup> Interpreted according to Landis and Koch (1977).

Results show ratings of categories of responses carried poor to substantial agreement, 75% were slight to fair, 25% moderate to substantial. This suggests that choice of closed ended answers by CFS sufferers, will vary in stability over time, and will vary more than the open ended answers.

**3.5.3 Internal Consistency IS-CFS**

Cronbachs Alpha was calculated to determine the homogeneity of the 12 items used to measure interpretations of questionnaires. A summary of Alpha values ("if each item were deleted from the questionnaire") is presented in Table 14 for the open ended responses, in Table 15 for the closed

responses.

**Table 14** *Internal Consistency Alpha values for IS-CFS<sup>a</sup> open ended responses if each item were deleted from the questionnaire, N=64.*

Cronbach's Alpha for whole scale = .72	
Question	Alpha if item deleted
1. You have tense muscles. Why?	.71
2. You notice that you cannot concentrate. Why?	.68
3. You have abdominal pain and diarrhoea. Why?	.71
4. You have recently lost weight without trying. Why?	.72
5. You have been waking in the early hours of the morning. Why?	.71
6. You are having difficulty focusing your attention. Why?	.68
7. You find you are having to urinate more frequently throughout the day. Why?	.71
8. You are feeling tired. Why?	.69
9. Your heart is pounding. Why?	.70
10. You are lacking energy. Why?	.68
11. You are experiencing headaches. Why?	.69
12. You are feeling on edge. Why?	.73

<sup>a</sup> IS-CFS Interpretations of symptoms in Chronic Fatigue Syndrome questionnaire.

**Table 15** *Internal Consistency Alpha values for IS-CFS<sup>a</sup> closed ended responses if each item were deleted from the questionnaire, N=77.*

Cronbach's Alpha for whole scale = .81	
Question	Alpha if item deleted
1. You have tense muscles. Why?	.79
2. You notice that you cannot concentrate. Why?	.79
3. You have abdominal pain and diarrhoea. Why?	.78
4. You have recently lost weight without trying. Why?	.79
5. You have been waking in the early hours of the morning. Why?	.77
6. You are having difficulty focusing your attention. Why?	.80
7. You find you are having to urinate more frequently throughout the day. Why?	.78
8. You are feeling tired. Why?	.78
9. Your heart is pounding. Why?	.78
10. You are lacking energy. Why?	.79
11. You are experiencing headaches. Why?	.81
12. You are feeling on edge. Why?	.80

<sup>a</sup> IS-CFS Interpretations of symptoms in Chronic Fatigue Syndrome questionnaire.

The result of the analysis shows that internal consistency of the scale is high, with an overall Cronbach's Alpha value of .81 for closed ended responses and .72 for open ended responses. When items were analysed individually there were none that would have significantly altered the overall alpha value if removed.



### 3.5.4 Summary of psychometric properties of IS-CFS

The assessment of inter-rater reliability of IS-CFS suggested categorisation of open ended answers by raters, seemed to be relatively simple. Inter-rater reliability was scoring almost perfect to perfect agreement 91.6% of the time. Test re-test data, over a period of 4-6 weeks, showed the choice of experimenter provided explanations by participants, to be less reliable than the open ended responses participants provided for themselves. Open ended responses produced 50% substantial to perfect agreement over time, ranking of the negative mood/cognitions answer from the closed ended responses produced 25% moderate to substantial agreement. Internal consistency was good, ranging overall from Cronbach's Alpha of .72 for the open ended answers to .81 for ranking of negative mood in closed ended responses.

**3.6 AIM 1.** Aim 1, in addition to developing the IS-CFS questionnaire (see above), seeks to provide information about the interpretations CFS sufferers have about their symptoms, specifically with reference to psychological explanations, and to compare these with interpretations of similar symptoms by the control groups.

#### Hypothesis 1:

**H1** CFS sufferers are less likely to interpret symptoms as evidence of depression than other comparison groups.

From the open ended answers, the sum of answers was calculated for each category, across groups. The purpose was to track the negative mood score across groups to discover whether the CFS group was avoiding this category as an explanation for the symptoms described. A new category of "any mood explanation" (positive and negative mood/cognitions numbers combined) was created to discover whether the CFS group were also avoiding mood explanations altogether (including positive mood/cognitions) for the symptoms in each item. In addition the illness explanation and the normal explanations were also tracked.

Where comparison of groups scores were required the non-parametric Kruskal-Wallis one-way analysis of variance was used as some between group variances were unequal (at  $p < .05$  using

Levene's test for equality of variances). Mann-Whitney U - Wilcoxon Rank Sum W tests ( $p < .05$ ) were used to locate the source of any significant differences found between groups.

A summary of this data appears in Table 14.

**Table 14** *IS-CFS<sup>f</sup> results showing endorsement of different categories of open ended answers across groups. (The larger the number the greater the endorsement).*

	CFS <sup>a</sup> (N=19)	DEP <sup>b</sup> (N=18)	MS <sup>c</sup> (N=19)	WK <sup>d</sup> (N=28)
<b>Explanation Categories</b>				
<b>Mean (sd)<sup>e</sup></b>				
Negative mood/cognitions	1.63 <sup>a</sup> (1.38)	7.53 (1.87)	3.06 <sup>b</sup> (1.64)	4.32 <sup>b</sup> (2.23)
Any mood/cognitions	1.89 <sup>a</sup> (1.79)	7.58 (1.94)	3.18 <sup>b</sup> (1.85)	4.57 <sup>c</sup> (2.2)
Illness	2.84 <sup>a</sup> (2.29)	0.47 (0.72)	1.88 <sup>ab</sup> (1.41)	1.18 <sup>b</sup> (1.16)
Normal reaction	7.11 <sup>a</sup> (2.02)	3.53 (1.74)	5.67 <sup>b</sup> (1.91)	6.18 <sup>ab</sup> (2.37)

<sup>a</sup>Chronic Fatigue Syndrome Group <sup>b</sup>Depressed Group <sup>c</sup>Multiple Sclerosis Group <sup>d</sup>Working Group; <sup>e</sup> Standard Deviation; <sup>a b c</sup> Within each measure means with different superscripts (including lack of superscript) are significantly different from each other; <sup>f</sup> IS-CFS Interpretation of symptoms in Chronic Fatigue Syndrome.

Results show the CFS group preferring the normal reaction explanation for symptoms followed by an illness explanation, any mood/cognitions explanations are avoided, especially negative ones. The CFS group endorses the normal reaction explanation at a similar level to the working group, as if their experience in this case is similar to participants who have not been ill in the last year (Robins, 1991). However they score significantly differently from the working group by endorsing the mood/cognitions explanations less and the infection or physical illness explanations more. The CFS group appear to be answering significantly differently from the depressed group, who have a psychological diagnosis for their symptoms, in every category. However they answer in a similar way to the MS group, who have a physical diagnosis for their symptoms, for the illness explanation, but endorse the mood/cognitions explanation less.

Results from the experimenter provided closed explanations show the mean sum of the ranking for the negative mood explanation, across groups. Results for this are presented in Table



15.

**Table 15** *IS-CFS<sup>f</sup> results showing mean sum of ranking of experimenter provided negative mood closed answers across groups. (The smaller the number, the greater the endorsement).*

	CFS <sup>a</sup> (N=19)	DEP <sup>b</sup> (N=18)	MS <sup>c</sup> (N=19)	WK <sup>d</sup> (N=28)
Negative mood category 3 item qs.	17.5 <sup>b</sup> (2.19)	11.4 (2.38)	14.5 <sup>a</sup> (2.85)	16.21 <sup>ab</sup> (2.83)
Negative mood category 4 item qs.	12.1 <sup>b</sup> (2.9)	5.89 (1.7)	9.4 <sup>a</sup> (2.1)	11.1 <sup>ab</sup> (2.75)

<sup>a</sup>Chronic Fatigue Syndrome Group <sup>b</sup>Depressed Group <sup>c</sup>Multiple Sclerosis Group <sup>d</sup>Working Group; <sup>e</sup> Standard Deviation; <sup>a b c</sup> Within each measure means with different superscripts (including lack of superscript) are significantly different from each other; <sup>f</sup> IS-CFS Interpretation of symptoms in Chronic Fatigue Syndrome.

Results in table 15 shows the CFS group endorsing the negative mood/cognition answer significantly less than the depressed and the MS group, and similarly to the working group.

### 3.6.1 Summary of Aim 1

The IS-CFS appears to have high inter-rater reliability. Test re-test reliability shows some items hold up over time and others are less reliable. The open ended format produces more answers which hold up substantially or better over time, than the experimenter generated explanations. Presumably this result is due to the open ended responses being more relevant to the participants' own experiences. However the experimenter generated explanations produce results which confirm the direction of the open ended responses, and therefore contribute to the internal consistency of the measure. They also provide an indication of the participants preference when the open ended response is unclear.

Results from the IS-CFS when compared between groups suggest the CFS group chose a mood/cognition explanation for symptoms less often than the other groups and endorses illness or normalising explanations in preference. Implications for this result will be considered in the discussion. There seems no evidence to reject Hypothesis 1.

**3.7 AIM 2.** Aim 2 will be focused on providing empirical evidence for the clinical observations of Surawy *et al.*(1995). In order to do this, the study aims to gather data about,



personality profiles of CFS sufferers.

## **Hypothesis 2:**

**H1** CFS sufferers are more likely than the comparison groups to have stronger beliefs about perfectionism, emotional strength, control and personal standards.

### **3.7.1 Dysfunctional attitudes Scale.**

Where comparison of groups scores were required the non-parametric Kruskal-Wallis one-way analysis of variance was used as some between group variances were unequal (at  $p < .05$  using Levene's test for equality of variances). Mann-Whitney U - Wilcoxon Rank Sum W tests were used to locate the source of any significant differences found between groups.

The three sub-scales measure attitudes to Achievement, Dependency and Self-Control which indicate a rate of depression-specific vulnerability factors. The Achievement subscale includes measures of both achievement and fear of failure; the Dependency subscale measures dependency on others and need for approval from others; the Self-Control subscale measures self-control issues in particular in relation to anxiety. Results from the DAS show the CFS group scoring overall significantly lower than the depressed group and at a similar level to the working group, Table 16. Subscales show a similar pattern with the CFS group scoring the lowest on all three measures, but similarly to the MS and working groups.

Results from the perfectionism measure are summarised in Table 17 and show the CFS group scoring lower than the other groups on a total measure of perfectionism. This is significantly different from the depressed group who score the highest. There is no difference between the groups in the subscales measuring *Personal Standards*, *Parental Expectations*, and *Organisation*. Scores for *Concern over Mistakes*, and *Doubts about Actions* show significant difference between the depressed group and the other 3 groups, with the CFS group scoring lowest of those three. *Parental Criticism* is scored lowest by the CFS and MS groups with significant differences between these and the depressed group.

**Table 17** *Perfectionism scale: mean scores and standard deviations between groups.*

	CFS <sup>a</sup> (N=19)	DEP <sup>b</sup> (N=18)	MS <sup>c</sup> (N=19)	WK <sup>d</sup> (N=20)
<b>Perfectionism scale</b>				
Mean (sd) <sup>e</sup> of total score	87.74 <sup>a</sup> (20)	124.83(24.4)	99.74 <sup>a</sup> (38.9)	97.82 <sup>a</sup> (27.8)
Subscale means (sd):				
Concern over mistakes	14.84 <sup>a</sup> (7.9)	34.27 (8.9)	21.32 <sup>a</sup> (14.9)	19.11 <sup>a</sup> (9.7)
Personal Standards	23.47 (5.9)	26.33 (7.9)	23.52 (11.1)	23.92 (7.5)
Parental Expectations	10.47 (6.5)	12.72 (7.6)	9.8 (7.9)	13.5 (7.6)
Parental Criticism	5.94 <sup>a</sup> (4.8)	11.11(6.2)	6.21 <sup>a</sup> (5.6)	7.14 <sup>a</sup> (5.1)
Doubts about Actions	7.57 <sup>a</sup> (4.3)	15.17 (4.7)	11.05 <sup>a</sup> (5.4)	9.64 <sup>a</sup> (4.2)
Organization	25.42 (5)	25.22 (6.3)	27.78 (7.3)	24.5 (6.9)

<sup>a</sup>Chronic Fatigue Syndrome Group <sup>b</sup>Depressed Group <sup>c</sup>Multiple Sclerosis Group <sup>d</sup>Working Group; <sup>e</sup> Standard Deviation; <sup>a b c</sup> Within each measure means with different superscripts (including lack of superscript) are significantly different from each other.

### 3.7.3 Summary Aim 2

#### Hypothesis 2:

**H1** CFS sufferers are more likely than the comparison groups to have stronger beliefs about emotional strength, control and personal standards.

The overall picture of the above results suggests that the CFS group is scoring on standard measures similarly to the working or MS group, but usually the lowest of the four groups. The characteristics of perfectionism, dysfunctional attitudes are not being endorsed. The group does



not appear to be depressed from the HADS although levels are higher than the working group, however CFS anxiety levels are the lowest of the four. They appear to have a consistently low score where a high score might have been expected from the literature (Surawy, 1995), hypothesis 2 would therefore be rejected.

**3.8 AIM 3.** Aim 3 will investigate the speculations of Ray (1991) and Surawy that the CFS personality profile resembles that of Beck's autonomous personality.

### **Hypothesis 3:**

**H1** CFS sufferers will score higher on measures of autonomy than either of the other three groups.

#### **3.8.1 Personal style Inventory**

The PSI measures concerns about interpersonal relationships (Sociotropy) and autonomous achievement (Autonomy). These are constructs which have been proposed to confer vulnerability to different kinds of depression, discussed in the Introduction.

The non-parametric Kruskal-Wallis one-way analysis of variance was used as some between group variances were unequal (at  $p < .05$  using Levene's test for equality of variances). Post hoc tests were carried out to locate the source of any significant differences found using the Mann-Whitney U - Wilcoxon Rank Sum W tests ( $p < .05$ ).

Results from this measure are summarised in Table 18. These show the CFS group scoring lower than the other 3 groups in total mean scores for both the sociotropic and autonomous scales. For the Autonomy scale this is significantly different, for the sociotropy scale this is significantly lower than the depressed and MS group but not from the working group. Subscales for the autonomy measure show the CFS group scoring the lowest but not significantly lower than the working group in the *perfectionism/selfcriticism* scale, and from the working group and the MS group in *need for control* and *defensive separation* scores. A similar pattern is found in the sociotropy subscales with CFS group means the lowest of the four groups in *Concern About What*



*Others Think* and *Pleasing Others* but not significantly lower than the MS and working group. However the score for *Dependency* is significantly lower than the other 3 groups.

**Table 18**      *Differences between groups on scores of Autonomy and Sociotropy using non-parametric 1-way anova.*

	CFS <sup>a</sup> (N=19)	DEP <sup>b</sup> (N=18)	MS <sup>c</sup> (N=19)	WK <sup>d</sup> (N=28)
<b>Autonomy total mean scores (sd)<sup>e</sup></b>	<b>75.47<sup>a</sup>(14)</b>	<b>96.00 (12.7)</b>	<b>85.31 (17.6)</b>	<b>76.32 (13)</b>
Subscale mean scores (sd) :				
Autonomy - Perfectionism/Self-Criticism	12.36 <sup>a</sup> (3.9)	19.11 (2.50)	15.78 <sup>b</sup> (3.7)	14.35 <sup>ab</sup> (3.5)
Autonomy - Need for Control	26.63 <sup>ab</sup> (7)	31.44 <sup>b</sup> (4.6)	29.21 <sup>ab</sup> (6.1)	25.85 <sup>a</sup> (6.2)
Autonomy - Defensive Separation	36.47 <sup>a</sup> (5.9)	45.44 <sup>b</sup> (9.4)	40.31 <sup>ab</sup> (10.2)	36.11 <sup>a</sup> (7.9)
<b>Sociotropy total mean scores (sd)</b>	<b>81.32<sup>a</sup>(17)</b>	<b>105.83<sup>c</sup>(15.3)</b>	<b>96.42<sup>bc</sup>(17.7)</b>	<b>90.96<sup>ab</sup>(15.1)</b>
Subscale mean scores (sd):				
Sociotropy - Concern About What Others Think	22.79 <sup>a</sup> (6.4)	31.28 <sup>b</sup> (5.5)	27.68 <sup>ab</sup> (7.3)	26.35 <sup>ab</sup> (5.7)
Sociotropy - Dependency	21.05 (6.2)	30.00 <sup>a</sup> (4.9)	28.05 <sup>a</sup> (5)	25.57 <sup>a</sup> (5.7)
Sociotropy - Pleasing Others	37.47 <sup>a</sup> (7.2)	44.55 <sup>b</sup> (8)	40.68 <sup>ab</sup> (7.5)	39.04 <sup>ab</sup> (6.8)

<sup>a</sup>Chronic Fatigue Syndrome Group <sup>b</sup>Depressed Group <sup>c</sup>Multiple Sclerosis Group <sup>d</sup>Working Group; <sup>e</sup> Standard Deviation; <sup>a b c</sup> Within each measure means with different superscripts (including lack of superscript) are significantly different from each other.

Robins *et al.*, (1994) found overall levels of sociotropy and autonomy in undergraduate student populations ranging from 95.8 sd=15.9 to 99.1 sd=18.4, and 82.6 sd=15.1 to 88.9 sd=16.1 respectively. Overall scores for the CFS group were lower than these, as were the working group. Average age of groups may have influenced this data as the average age in this study was 40 years. However Robins has not commented on difference in scores across age groups.

Results from the PSI show the CFS group scoring lower on levels of autonomy and sociotropy than the other 3 groups. This is significantly different from all 3 groups for total

autonomy scores, and similar to the working group in the total sociotropy score. The subscales demonstrate a similar pattern. Hypothesis 3 that CFS sufferers will score higher on measures of autonomy than either of the other three groups, is therefore rejected.

## **4. DISCUSSION**

### **4.1 OVERVIEW**

This study was divided into two main parts. The first described the preliminary piloting of items for the IS-CFS. The second part of the study used the IS-CFS in conjunction with standard measures to test hypotheses about CFS sufferers' personality characteristics, in comparison with a group of depressed patients and a group of patients suffering with multiple sclerosis. In addition a working group of people were used as a "normal" control.

A summary of results will be presented including the reliability and validity of the piloted measure. The second section of the discussion will present a summary of the results from the testing of the hypotheses, and will be followed by a discussion of methodological considerations. Finally implications from the findings for clinical practice and future research will be considered.

### **4.2 SUMMARY OF RESULTS**

The overall aim of the study was to gather data about CFS sufferers in order to make a theoretical contribution to the understanding of CFS within a CBT framework, and to contribute to a common understanding between physician and patient.

Aim 1 was to investigate interpretations CFS sufferers have about their symptoms, specifically with reference to psychological factors and depression, and to compare these with interpretations of similar symptoms by the control groups. In order to do this the IS-CFS was developed. After piloting the measure and altering aspects of the items and the categorisation of open ended answers, the measure was subject to further tests of reliability and validity in the main study.

Inter-rater reliability for the IS-CFS scored almost perfect to perfect agreement 91.6% of the time. Test re-test data, over a period of 4-6 weeks, showed the choice of experimenter provided explanations by participants, to be less reliable than the open ended responses participants provided for themselves. Open ended responses produced 50% substantial to perfect agreement



over time, ranking of the negative mood/cognitions answer from the closed ended responses produced 25% moderate to substantial agreement. Internal consistency was good, ranging overall from Cronbach's Alpha of .72 for the open ended answers to .81 for ranking of negative mood in closed ended responses.

Although the IS-CFS was considered robust enough to produce reliable data for the main study, it is considered that further research could improve this measure considerably. Test re-test results show a lower level of agreement than might be hoped from a measure trying to assess stait type interpretations. Results suggest that some of the items may be mood-state reliant, either these need to be modified or removed. Possible uses for the measure in the future might be as part of diagnosis, in order to assess the strength of illness convictions, or resistance to psychological ideas in relation to symptoms. It might also be developed in order to distinguish those with predominantly depression from those whose fatigue is the dominant problem.

The data provided by this measure in the main study was used to test the first hypothesis; that CFS sufferers are less likely to interpret symptoms as evidence of depression than other comparison groups. Evident from the data was the tendency for the CFS group to endorse illness or normalising explanations in preference to psychological (mood/cognition) explanations for symptoms typical of CFS. Data suggests that symptoms would be less likely to interpreted as evidence of depression, and the hypothesis is therefore not rejected.

The second aim was to investigate evidence for the clinical observations of Surawy *et al.*(1995) about personality characteristics of CFS patients including: high personal standards, achievement, self-control, conscientiousness, responsibility, the consequence of failure, psychological strength, suppression of negative emotions, pleasing others and meeting others needs. These were measured by the Dysfunctional Attitudes Scale and the Perfectionism scale, with the Hospital Anxiety and Depression scale to monitor mood. The second hypothesis that CFS sufferers were more likely than the comparison groups to have stronger beliefs about perfectionism, emotional strength, control and personal standards was not supported by the results. Trends in the data showed the CFS group is scoring consistently lower than the other

groups on measures of perfectionism and dysfunctional attitudes. Their mood was at a similar level to the MS group, significantly higher than the working group but not in the depressed or anxious range. They appear to have a consistently low score where a high score might have been expected from clinical observations (Surawy, 1995). Surawy noted the personality characteristics mentioned above as particularly relevant to the CFS sufferer and part of the mechanism by which the illness can be maintained (See Appendix 1).

The third aim was to investigate the speculations of Ray (1991) and Surawy that the CFS personality profile resembles that of Beck's autonomous personality. The hypothesis that CFS sufferers will score higher on measures of autonomy than either of the other three groups was not upheld. The CFS group scored significantly lower than the other groups on measures of autonomy and as low as the working group in measures of sociotropy. Ray (1991) and Surawy (1995) speculated that the CFS sufferer was similar to Beck's autonomous personality when in a state of depression in every way except for the maintenance of self esteem. They both noted it was the external illness attribution which helped self esteem remain high.

### 4.3 SUMMARY

If trends in the data are to be taken at their face value, the CFS participant group appear to be low in depression and anxiety, of a non-perfectionistic nature, with low levels of dysfunctional assumptions about the importance of achievement, dependency and self-control. They also appear to have low scores of either sociotropic or autonomous personality characteristics, thus protected from depression precipitated either by failure of social relationships or failure to maintain autonomous achievement. In addition they reject a psychological (emotion/cognition) based explanation for symptoms typical of CFS.

The results from the data summarised above, could be due to a number of reasons, the first of which is that data reflects a true picture of the CFS sufferer. Alternatively the CFS personality fits the description of the "pseudo-healthy" individual (Weinberger *et al.*, 1979) who despite scoring low on levels of symptomatology, would score high on levels of defensiveness.



Personality measure results are either in direct contradiction to the clinical findings of Surawy (1996) if taken at face value, or, it can be speculated, confirm the findings, by presenting a personality who is completing the questionnaires in a defensive manner to avoid appearing psychologically weak or a failure. Other possible reasons for these results may involve methodological problems, these are discussed below.

#### **4.4 METHODOLOGICAL ISSUES**

There were several limitations to this study, these include the recruitment of participants, the use of the questionnaire format and the influence of mood on responses to personality measures. These point will be discussed in the following section.

##### **4.4.1 Recruitment of participants**

As both the CFS and MS groups were sampled from specialist hospital practice and were already part of ongoing trials, these results cannot be applied to primary care. Particularly the MS group were very motivated and this may account for the high return rate for this group. Depressed patients were partly drawn from G.P. surgeries but also from Hospital outpatients clinic and therefore may be more typical of the general population of depressed people. The working group were recruited from a university town with 82% of the group educated beyond 18 years and in social class 1 and 2. This calls into doubt the "normality" of this working group, compared with a working population in another area. Results must therefore be treated with caution, and further investigations need to be made with a population more typical of those in primary care.

Data showing mood levels of CFS participants did not replicate that found by Wessely & Powell (1989). Wessely found 47% of CFS participants also had a diagnosis of major depression. Levels of depression were much lower in the current study. However Wessely also found that 28% of CFS participants had no psychiatric disorder, and White described a group of CFS sufferers who had low mood scores, were over controlled and defensive and did not describe themselves as psychologically deviant. This conforms closely to the ICD-10 description of



Neurasthenia, where despite the presence of fatigue, weakness and exhaustion after minimal effort, depression and anxiety are absent. It is speculated that the current study has a greater percentage of these participants, and therefore this study is measuring a particular group within the heterogeneous population of CFS sufferers.

There is no data on the CFS patients who were contacted but who declined to take part. They may represent a group of different types of fatigue cases, and therefore interesting to this study, as such they might shed light on different aspects of CFS. In addition, no distinction was made between CFS patients who had been ill for different lengths of time. Importance of factors may vary at different stages of CFS.

Numbers of participants in each group were small and further research should attempt to gather data from large enough groups in order to take in effects of gender, age and chronicity of illness.

#### 4.4.2 The use of questionnaires

As discussed above, the results of data might be used as evidence to undermine the findings of Surawy (1995) in clinical treatment. However her research was made with over 100 subjects and over a space of years and is unlikely to be inaccurate. The standard measures used have proven high levels of reliability and validity. Potential drawbacks in using questionnaires with CFS sufferers, and others who score high on social desirability, were discussed in the Introduction. Consistently low scores on measures where clinical practice would suggest the opposite result found in this study, might be interpreted as a conscious or subconscious response style indicating defensiveness against appearing psychologically weak or a failure (Ray, 1991). Results of this study replicate Sharpe's (in press) findings in CFS patients scoring high on social desirability and low on perfectionism scores.

Methodological improvements to research with CFS sufferers could be made in a number of ways to avoid participants responding according to an idealised image of themselves. These might include; qualitative methods, the use of experimental tasks and other more opaque measures

which could not be consciously manipulated, the use of other informants who know the patient well, to reflect on the CFS sufferers personality, motivations and lifestyle, or in a comparative study of ideal images of self. These will be discussed below.

Andrews & Brown (1993) concluded that interview based research by experts was superior to individuals' self reports. Qualitative research and interviews have proved an important alternative to questionnaire studies with this patient group. Clements has used this methodology to provide insight into the subtleties of meaning in the use of the word "Stress" and its role in accepting the role of psychological factors in the aetiology of CFS.

The use of experimental tasks may enable the assessment of automatic as well as controlled processes. Toner has suggested the modification of the Self-Referent Encoding Task (SRET) to demonstrate the difference in self-schemas between CFS patients and other patient groups. This might be also useful in distinguishing differing groups within the heterogeneous picture of CFS. The difference in schema might also be a useful diagnostic aid. The same might be done with the emotional Stroop test.

In addition other informants could be used to test the theory that CFS participants score questionnaires in a socially acceptable manner. A normal group of participants could be assigned the task of completing questionnaires as if they were "super" normal and solid with no psychological or physical complications. These could be compared with the results from CFS sufferers to see if they produced the same pattern.

#### **4.4.3 The influence of mood on responses to personality measures**

The depressed group answered significantly differently from the other 3 groups on the standard measures, which questions whether the standard measures were measuring mood to a large extent. There is evidence that measures of dysfunctional attitudes in general are quite strongly influenced by the presence of a depressed mood state (Power *et al.*, 1995).

There is also evidence that such attitudes and personality characteristics persist, beyond the depressed state (Miranda & Persons, 1988). Power (Power *et al.*, 1995) supported the idea that a



core set of dysfunctional beliefs or attitudes are active during recovery and that these form part of the core cognitive vulnerability to depression. To overcome this methodological problem, the current study had a potential group of recovered depressed patients who could have been used as a fourth comparison group. Any differences in personality characteristics found between this group, the currently depressed group and the CFS group might have produced interesting results. Unfortunately the fifth group only contained 10 participants, not enough to produce reliable statistical evidence. It is recommended that this comparison be made in future studies.

#### 4.5 CLINICAL IMPLICATIONS

Results from this study show levels of disability are high in the CFS group; their scores for concentration and memory problems resembled the level of the depressed group, however they report more time off work, and fewer percentage of the group work full time than either of the other patient groups. Any treatment that can alleviate severe physical and mental fatigue and enable CFS sufferers to return to a more normal lifestyle should be encouraged. CBT supplies a treatment option for sufferers from CFS which is sympathetic to their view of their symptoms, but at the same time will not deny the possible psychological aspects of their illness. The CBT model of treatment has been found to be effective.

Trends in the research data from this study indicate the extent to which the psychological aspect of symptoms may be rejected by such a patient group. If CFS sufferers are to be helped the extent of this must be recognised by physicians, both specialists and G.P.s and methods of communicating more effectively about the nature of symptoms devised. This would be particularly important for G.P.s to understand as this is the first contact with the medical profession for the CFS sufferer.

The CBT approach tries to do this by sharing a multi-axial framework within which symptoms can be discussed. Thus it does not deny the extent to which other aspects of the illness such as physical infection, social factors, illness behaviour and personality are influential. This approach is of more help to a patient group who do not always share the dichotomous reasoning of



the press and other self-help books, where the psychological explanation is pitted against the physical explanation in an unhelpful way. CFS sufferers are able to integrate the importance of stress into their picture of the aetiology of their illness and this needs to be acknowledged by physicians.

Knowledge of the current state of research into CFS by psychologists need to be given as much publicity as other approaches to the illness. A self help book incorporating the multiaxial approach would contribute much to the understanding of CFS and help discharge the atmosphere surrounding the subject.

The overall aim of this study was to gather data about CFS sufferers in order to make a theoretical contribution to the understanding of CFS within a CBT framework. Results have broadened the clinical picture of CFS sufferers, describing presumed defensiveness in completion of measures, and anti-psychological thinking about symptoms. The research has contributed a picture which would fit well into the multiaxial approach, which, if promoted, could help to create a common understanding between physician and patient.

#### **4.6 IMPLICATIONS FOR FURTHER RESEARCH**

The need for further research into CFS is evident. The heterogeneous nature of the illness makes definition of the syndrome complicated. Further investigations into the diverse nature of the symptoms and the different subgroups of patients (e.g. distinguishing those who do and do not show signs of depression), and whether or not prognosis for these groups vary, would further the effectiveness of treatment.

Research with those who feel they have recovered from CFS, would also shed some light on the problem. Sufferers from CFS who recover could be compared with those who do not recover over a long period of time, and those who do and do not recover from similarly partly unexplained illnesses such as Chronic Pain and Irritable Bowel Syndrome.

Both these aims would need to be investigated in research which covered a wide range of fatigued people from a community G.P. setting, in order to get a broader picture of fatigue and

fatigued states in the community. Working with participants who felt they had recovered from CFS would provide a body of data on beliefs and cognitions about recovery. This would also help to broaden treatment approaches and options, and hopefully increase effectiveness.

If methods of distinguishing between schemas of CFS sufferers and other related illnesses, which did not involve the use of questionnaires, were developed, this would also aid diagnosis and effectiveness of treatment.

#### 4.7 MAIN CONCLUSIONS

CFS is still a controversial illness, our understanding of it remains poor and positive approaches to treatment are few (Sharpe, 1996). However the cognitive behavioural model affords some hope for development of treatment in the future.

This study has compared a group of CFS sufferers with a depressed group and a group suffering from multiple sclerosis, and found the CFS group to be considerably disabled in comparison with them.

The CFS group has been shown to favour somatic explanations for symptoms rather than cognitive or emotional ones. The corollary of this is that CFS patients are likely to reject a psychological explanation for their own symptoms. It is speculated this is related to their avoidance of appearing psychologically weak and the perceived stigma associated with this. However questionnaires which attempt to define this have proved of little help with this patient group as it is speculated that they answer either consciously or unconsciously in a defensive manner. The outcome of this is to highlight the care that needs to be taken in communicating ideas about psychological aspects of CFS to sufferers.

There is ample room for research in this area, especially on schemas associated with this patient group, and with patients who have recovered from the illness spontaneously.

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**APPENDIX 1      CBT FORMULATION FOR CFS**

## Chronic Fatigue Syndrome

### Dysfunctional Assumptions

If I am to be acceptable to myself and to others I must

(a) achieve high standards of performance and responsibility

(b) be in control of my emotions and not display weakness



### Premorbid behaviour

Strive for high standards. Do not complain or admit to any weakness. Neglect own needs



### Critical Incidents

Excessive demands (eg prolonged work stress) or reduced ability to meet demands

(eg emotional consequences of life events, viral illness) leading to failure to meet

### requirements of assumptions



#### Behaviour

Try harder

Do not complain

#### Emotion

Frustration

Distress

#### Symptoms

Fatigue

Autonomic arousal

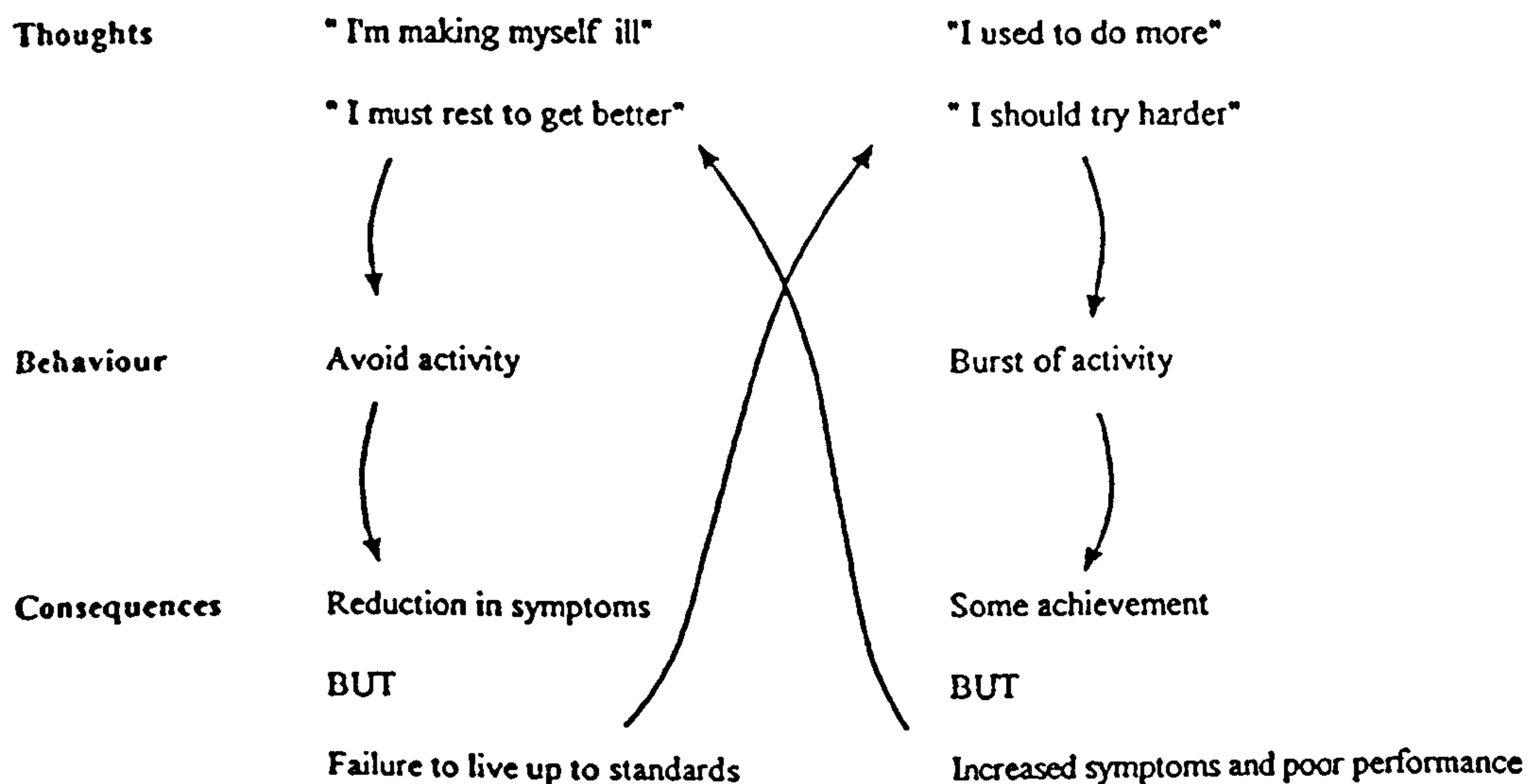
#### Thoughts

Why am I not coping?

I must be physically ill

### Theoretical cognitive model of aetiology of CFS

A vicious cycle alternating between frustrated effort and ineffectual rest, maintained by the attribution of symptoms to disease, traps the patient in chronic illness. Oscillations in activity precludes the attainment of any sustainable increase in the capacity for activity. A focus on disease distracts the patient from tackling psychological and social difficulties.



### The perpetuation of CFS



## **APPENDIX 2      COVERING LETTER FOR PILOT STUDY**

# **PERSONAL ATTITUDES AND EXPERIENCES OF ILLNESS PROJECT**

Cotswold House, Warneford Hospital, Oxford OX3 7JX.  
Tel: 01865 226247

Dear Colleague,

I am writing to ask for your help in piloting the enclosed questionnaire.

Your participation will greatly help in research currently being carried out which aims to increase our understanding of chronic fatigue and related illnesses. It is hoped to collect data from a group of around 20 people, both men and women, currently physically and emotionally well. Such a group will allow me to compare certain characteristics of a healthy population with those of patients with persistent fatigue and other related illnesses.

I would be grateful if you would consider completing the questionnaire if you are

1. currently physically and emotionally well and
2. have not suffered from any major physical or emotional problems in the last year

If you do not fit into the criteria outlined above, or if for any reason you do not want to complete the questionnaires, that is fine, just replace the questionnaire in my pigeon hole

An envelope has been included for you to return the questionnaires to me, I would be very grateful if you could do this within two weeks of having received them. I will be sending you this questionnaire again in 4-6 weeks for re test. Please contact me if you have any questions about the research.

With many thanks in anticipation of your help

Yours Sincerely

Ms Name.  
Oxford Mental Health Trust  
Department of Psychology

**APPENDIX 3      PANIC QUESTIONNAIRE CLARK**



Here are some outline descriptions of situations in which it is not quite clear what is happening. Read each one, then answer the question below it very briefly. Write down the first thing which comes into your mind, without thinking too long about it. Please write down what you think is happening before you turn over the page. Be as specific as possible.

When you have done that, turn over the page and you will see several possible explanations for the situation. Arrange these in the order in which they would be most likely to come to your mind if you found yourself in a similar situation. This means that the one which you are most likely to think would come 1st, the one you are least likely to think would come 3rd. Do not think too long before deciding. We want your first impressions; do not worry if none of them fits what you actually did think.

1. You notice that your heart is beating quickly and pounding.

Why?

1. a) Because you have been physically active.
- b) Because you are about to have a heart attack.
- c) Because your heart is beginning to show signs that it is slowly failing
- d) Because you are feeling excited.

1st..... 2nd..... 3rd..... 4th.....

2. You go into a shop and the assistant ignores you.

Why?

2. a) They are bored with their job, and this makes them rude.
- b) They are concentrating very hard on something else.
- c) They find you irritating and resent your presence.

1st..... 2nd..... 3rd.....

3. You have developed a small spot on the back of your hand.

Why?

3. a) You have been eating the wrong things or have a mild allergy.
- b) You are developing skin cancer.
- c) You have been bitten by an insect.

1st..... 2nd..... 3rd.....

4. You feel lightheaded and weak.

Why?

- 
4. a) You have the first signs of a serious progressive illness
- b) You need something to eat.
- c) You didn't get enough sleep last night.
- d) You are about to faint.

1st..... 2nd..... 3rd..... 4th.....

5. You wake with a start in the middle of the night, thinking you heard a noise, but all is quiet.

What woke you up?



5. a) You were woken by a dream.

b) A burglar broke into your house.

c) A door or window rattled in the wind.

1st..... 2nd..... 3rd.....

6. Your chest feels uncomfortable and tight.

Why?

6. a) You have indigestion.

b) Your heart is about to stop.

c) You have developed a chronic chest illness.

d) You have a sore muscle.

1st..... 2nd..... 3rd..... 4th.....

7. You have a sudden pain in your stomach.

Why?

7. a) You have an ulcer, appendicitis or other serious stomach disease.

b) You have indigestion.

c) You are hungry.

1st.....2nd.....3rd.....

8. You notice that the skin on your hands has become blotchy and red in places.

Why?

3. a) Because your hands are dry.

b) Because you are developing skin cancer or you have an illness which affects your circulation.

c) Because you have come out of the cold into the warm.

1st..... 2nd..... 3rd.....

9. You are introduced to someone at a party who fails to reply to a question you ask them.

Why?

9. a) They did not hear the question.

b) They think you are uninteresting and boring.

c) They were preoccupied with something else at the time.

1st..... 2nd..... 3rd.....

10. You have a pain in the small of your back.

Why?

10. a) You have pulled a muscle while bending and stretching.

b) You are sitting awkwardly.

c) There is something going wrong with one of your internal organs.

1st..... 2nd..... 3rd.....

11. You suddenly feel confused and are having difficulty in thinking straight.

Why?



11. a) You are about to go out of your mind or are  
having a stroke.

b) You've been working too hard and need a rest.

c) You have are starting to develop a brain disease  
or are slowly losing your grip on reality.

d) You are coming down with a cold.

1st..... 2nd..... 3rd..... 4th.....

12. You have visitors round for a meal and they leave  
sooner than you expected.

Why?

12. a) They did not wish to outstay their welcome.

b) They had another pressing engagement to go to.

c) They did not enjoy the visit and were bored with  
your company.

1st..... 2nd..... 3rd.....

13. You find a lump under the skin on your neck.

Why?

13. a) You have a mild cold virus and your glands are slightly swollen.

b) The lump is normally there, but you have just noticed it.

c) You are developing cancer.

1st..... 2nd..... 3rd.....

14. You feel short of breath.

Why?

14. a) You are developing flu.

b) You are about to suffocate or stop breathing.

c) You are physically "out of shape".

d) You are having the first signs of slow, progressive heart or lung damage.

1st..... 2nd..... 3rd..... 4th.....

15. A letter marked 'URGENT' arrives.

What is in the letter?

15. a) It is a circular designed to attract your attention.
- b) You forgot to pay a bill.
- c) News that someone you know has died or is seriously ill.

1st..... 2nd..... 3rd.....

16. A friend suggests that you change the way that you're doing a job in your own house.

Why?

15. a) They are trying to be helpful.
- b) They think you're incompetent
- c) They have done the job more often and know an easier way.

1st..... 2nd..... 3rd.....

17. You notice that your heart is pounding, you feel breathless, dizzy and unreal.

Why?



17. a) You have been overdoing it and are overtired.

b) You have the early signs of a serious heart complaint.

c) Something you ate disagreed with you.

d) You are dangerously ill or going mad right now.

1st..... 2nd..... 3rd..... 4th.....

18. You have been eating normally but have recently lost some weight.

Why?

18. a) You have cancer.

b) It's a normal fluctuation.

c) You have been rushing about more than usual.

1st..... 2nd..... 3rd.....

19. You smell smoke.

What's burning?

19. a) Your house is on fire.

b) Some food is burning.

c) Someone is smoking a cigarette.

1st..... 2nd..... 3rd.....

20. Your vision has become slightly blurred.

Why?

20. a) You have strained your eyes slightly.

b) You need to get glasses or change your existing  
glasses.

c) This is an early sign of a serious illness.

1st..... 2nd..... 3rd.....

## **APPENDIX 4      PILOT COPY OF IS-CFS**



## Interpretations

Here are some outline descriptions of situations in which it is not quite clear what is happening. Read each one, then answer the question below it very briefly. Write down the first thing which comes into your mind, without thinking too long about it. Please write down what you think is happening before you turn over the page. Be as specific as possible. When you have done that, turn over the page and you will see several possible explanations for the situation. Number these in the order in which they would be most likely to come to your mind if you found yourself in a similar situation. This means that the one you are most likely to think would become number 1, the next 2, the next 3 etc. Do not think too long before deciding. We want your first impressions; do not worry if none of them fits what you actually did think.

- 
1. You notice that you cannot concentrate.

Why?

I am worried about something

1.

- a. You are tired and need a rest.
- b. There is nothing wrong with this, some days concentration is just better than others.
- c. You are fed up.
- d. You are distracted by pleasurable thoughts.

1st...*a*... 2nd...*b*... 3rd...*d*... 4th...*c*...

2.

You have abdominal pain and diarrhoea.

Why? *I have eaten something rotten*

---

2.

- a. You are worried and anxious about problems.
- b. You have irritable bowel syndrome.
- c. The natural balance of your gut has been put out by something you have eaten, it can easily be restored.

1st...*c*... 2nd...*a*... 3rd...*b*...

3.

You have been waking in the early hours of the morning.

Why?

*Something exciting is about to happen.*

3.

- a. You were woken by anxious thoughts which will not go away.
- b. You were woken by harmless noises in the house.
- c. You are developing problems with your sleep rhythm.

1st...*a*... 2nd...*b*... 3rd...*c*...

4.

You notice your memory is failing you.

Why? *I am tired*

---

4.

- a. You are depressed and are therefore concentrating less well.
- b. You are over excited about plans for your future, the present seems less important.
- c. It is to be expected, you have more things to think about than usual
- d. It's the effect of aging.

1st...*c*... 2nd...*b*... 3rd...*a*... 4th...*d*...

5.

You are experiencing headaches.

Why? *I am hungover.*



5.

- a. Your eyesight must have deteriorated.
- b. Headaches are a normal hazard of 20th century living.
- c. Unhappy thoughts are making you tense.

1st...*b*.... 2nd...*a*.... 3rd...*C*....

6.

You notice you have no enthusiasm for life.

Why? *I am working*

---

6.

- a. Everyone has their ups and downs.
- b. You are about to get 'flu.
- c. This is an early sign of depression.

1st...*a*.... 2nd...*b*.... 3rd...*C*....

7.

Your heart is pounding.

Why?

*Something important is about to happen.*

7.

- a. You have been over doing it and are over tired, you just need to slow down.
- b. It is due to anxiety.
- c. You are very excited about something.
- d. You are physically unwell.

1st...c... 2nd...b... 3rd...a... 4th...d...

8.

You notice you are feeling more tired than usual.

Why? I am working for 6 hours

---

8.

- a. You are burdened by depressive thoughts.
- b. You are pleasantly relaxed.
- c. You are getting a cold.
- d. This happens from time to time it is a normal fluctuation in energy levels.

1st...a... 2nd...c... 3rd...d... 4th...b...

9.

You have recently lost weight without trying.

Why?

I have been ill

9.

- a. You have a serious physical illness.
- b. It's just a natural variation.
- c. You are feeling very positive about yourself and are enjoying life
- d. You are becoming depressed and have lost your appetite.

1st...*a*... 2nd...*b*... 3rd...*c*... 4th...*d*...

10.

You notice you feel irritable and anxious in the evenings.

Why? *I am not getting enough sleep.*

---

10.

- a. It's lack of sleep.
- b. This is natural after a long day.
- c. You are depressed and pessimistic about unresolved problems.

1st...*a*... 2nd...*b*... 3rd...*c*...

11.

You seem to be constantly jumpy and alert.

Why?

*I have a lot of things on my mind*



11.

- a. You are under stress and are naturally more on edge at the moment.
- b. You are developing an anxiety state.
- c. It's the additives in processed food.

1st.....<sup>a</sup> 2nd.....<sup>c</sup> 3rd.....<sup>b</sup>

12.

You find you are having to urinate more frequently throughout the day.

Why?

*I have drunk more than usual.*

---

12.

- a. You are developing diabetes.
- b. You are anxious.
- c. You have been drinking more tea or coffee lately, you just need to cut down.

1st.....<sup>c</sup> 2nd.....<sup>b</sup> 3rd.....<sup>a</sup>

## **APPENDIX 5      FINAL VERSION OF IS-CFS**

## QUESTIONNAIRE 4

Here are some outline descriptions of situations in which it is not quite clear what is happening to you.

Read each one, then answer the question below it very briefly. Write down the first thing which comes into your mind, without thinking too long about it. Please write down what you think is happening to you before you turn over the page. Be as specific as possible.

Here is an example which has already been completed:

You are feeling very thirsty.  
Why?

*I need a drink.*

When you have done that, turn over the page and you will see other possible explanations for the same situation (do not worry if none of them matches what you have just written).



Arrange the explanations in the order in which they would be most likely to come to your mind, by writing the corresponding letters against **1st....., 2nd....., 3rd..... and 4th.....** choice.

see completed example below:

- a. You have been physically active and have been sweating.
- b. You are developing a fever.
- c. You drank too much alcohol and you are dehydrated.
- d. This is quite normal, you last had a drink hours ago.

1st.....*d*..... 2nd.....*a*..... 3rd.....*c*..... 4th.....*b*.....

Now turn the page and begin the questionnaire.

Do not think too long before answering, we want your first impressions.

1. You have tense muscles.  
Why?

1.
  - a. You have been more physically active than is usual for you.
  - b. You are feeling tense and anxious.
  - c. You are developing a fever.

1st..... 2nd..... 3rd.....

2. You notice that you cannot concentrate.  
Why?



- 2.
- a. You are tired and need a rest.
  - b. There is nothing wrong with this, some days concentration is just better than others.
  - c. You are fed up.
  - d. You are distracted by pleasant thoughts.

1st..... 2nd..... 3rd..... 4th.....

3. You have abdominal pain and diarrhoea.  
Why?

3.     a.     You are worried and anxious about problems.  
       b.     You have a stomach bug.  
       c.     The natural balance of your gut has been put out by something you have eaten,  
              it can easily be restored.

1st.....     2nd.....     3rd.....

4.     You have recently lost weight without trying.  
       Why?

4.     a.     You are physically unwell.  
       b.     It's just your natural variation.  
       c.     You are in love.     ^  
       d.     Feeling upset has made you lose your appetite.

1st.....    2nd.....    3rd.....    4th.....

5.     You have been waking in the early morning.     Why?



5.     a.     You are woken by anxious thoughts which will not go away.  
       b.     You are woken by harmless noises in the house.  
       c.     You are developing problems with your sleep rhythm.

1st.....    2nd.....    3rd.....

6.     You are having difficulty focussing your attention.  
       Why?

6.    a.    You are excited about something. .  
      b.    You are getting the 'flu.  
      c.    You are feeling depressed.  
      d.    There are just too many demands from others.

1st.....    2nd.....    3rd.....    4th.....

7.    You find you are having to urinate more frequently throughout the  
      day.  
      Why?

7.     a.     You are developing a urinary infection.  
       b.     You are anxious.  
       c.     You have been drinking too much fluid.

1st.....    2nd.....    3rd.....

8.           You are feeling tired.  
             Why?



- 8.
- a. You have been doing too much.
  - b. You have a virus.
  - c. You are over stressed.

1st..... 2nd..... 3rd.....

9. Your heart is pounding.  
Why?

- 9.
- a. It is due to anxiety.
  - b. You are very excited about something.
  - c. You are physically unwell.
  - d. You have been over doing it and are over tired, you just need to slow down.
- 1st..... 2nd..... 3rd..... 4th.....

10. You are lacking in energy.  
Why?

10.    a.    You need a holiday.  
      b.    You are feeling depressed.  
      c.    You are physically ill.

1st.....    2nd.....    -3rd.....

11.            You are experiencing headaches.  
              Why?



11. a. It's a virus.  
b. You are drinking too much tea or coffee.  
c. Worrying thoughts are making you tense.

1st..... 2nd..... 3rd.....

12. You find you are feeling on edge.  
Why?

12.
- a.

You are anxious.
- b.

You are over stimulated.
- c.

You have got too much to do.
- 1st.....

2nd.....

3rd.....

Time taken in minutes to complete the questionnaire: . . . . .

**APPENDIX 6     HADS**

# QUESTIONNAIRE 1

Please read each item and place a tick in the box opposite the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

*Tick only one box in each section*

**I feel tense or 'wound up':**

- Most of the time .....
- A lot of the time .....
- Time to time. Occasionally .....
- Not at all .....

<input checked="" type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>

**I feel as if I am slowed down:**

- Nearly all the time .....
- Very often .....
- Sometimes .....
- Not at all .....

<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

**I still enjoy the things I used to enjoy:**

- Definitely as much .....
- Not quite so much .....
- Only a little .....
- Hardly at all .....

<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>

**I get a sort of frightened feeling like 'butterflies' in the stomach:**

- Not at all .....
- Occasionally .....
- Quite often .....
- Very often .....

<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

**I get a sort of frightened feeling as if something awful is about to happen:**

- Very definitely and quite badly .....
- Yes, but not too badly .....
- A little, but it doesn't worry me .....
- Not at all .....

<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

**I have lost interest in my appearance:**

- Definitely .....
- I don't take so much care as I should .....
- I may not take quite as much care .....
- I take just as much care as ever .....

<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>

**I can laugh and see the funny side of things:**

- As much as I always could .....
- Not quite so much now .....
- Definitely not so much now .....
- Not at all .....

<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>

**I feel restless as if I have to be on the move:**

- Very much indeed .....
- Quite a lot .....
- Not very much .....
- Not at all .....

<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

**Worrying thoughts go through my mind:**

- A great deal of the time .....
- A lot of the time .....
- From time to time but not too often .....
- Only occasionally .....

<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

**I look forward with enjoyment to things:**

- As much as ever I did .....
- Rather less than I used to .....
- Definitely less than I used to .....
- Hardly at all .....

<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>

**I feel cheerful:**

- Not at all .....
- Not often .....
- Sometimes .....
- Most of the time .....

<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>

**I get sudden feelings of panic:**

- Very often indeed .....
- Quite often .....
- Not very often .....
- Not at all .....

<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

**I can sit at ease and feel relaxed:**

- Definitely .....
- Usually .....
- Not often .....
- Not at all .....

<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

**I can enjoy a good book or radio or TV programme:**

- Often .....
- Sometimes .....
- Not often .....
- Very seldom .....

<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>

**Time taken in minutes to complete the questionnaire.....**



**APPENDIX 7      SCORING BANDS FOR HADS**

### Scoring Bands for the HADS

Range of scores	Interpretation
0-7	normal
8-10	mild
11-14	moderate
15-21	severe

Snaith and Zigmond (1994)

**APPENDIX 8      DAS 24**

## QUESTIONNAIRE 2

This scale lists different attitudes or beliefs which people sometimes hold. Please read each statement carefully and decide how much you agree or disagree with what it says.

For each of the attitudes, please indicate your answer by placing a mark under the column that best describes how you think. Be sure to choose only one answer for each attitude. But please note that because people are different, there is no right or wrong answer to these statements.

To decide whether a given answer is typical of your way of looking at things, simply keep in mind what you are like for most of the time.

ATTITUDES	TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE
1. If I fail partly, it is as bad as being a complete failure							
2. If others dislike you, you cannot be happy							
3. I should be happy all the time							
4. People will probably think less of me if I make a mistake							
5. My happiness depends more on other people than it does on me							
6. I should always have complete control over my feelings							
7. My life is wasted unless I am a success							
8. What other people think about me is very important							
9. I ought to be able to solve my problems quickly and without a great deal of effort							
10. If I don't set the highest standards for myself, I am likely to end up a second rate person							
11. I am nothing if a person I love doesn't love me							
12. A person should be able to control what happens to him							



ATTITUDES	TOTALLY AGREE	AGREE VERY MUCH	AGREE SLIGHTLY	NEUTRAL	DISAGREE SLIGHTLY	DISAGREE VERY MUCH	TOTALLY DISAGREE
13. If I am to be a worthwhile person, I must be truly outstanding in at least one major respect							
14. If you don't have other people to lean on, you are bound to be sad							
15. It is possible for a person to be scolded and not get upset							
16. I must be a useful, productive, creative person or life has no purpose							
17. I can find happiness without being loved by another person							
18. A person should do well at everything he undertakes							
19. If I do not do well all the time, people will not respect me							
20. I do not need the approval of other people in order to be happy							
21. If I try hard enough, I should be able to excel at anything I attempt							
22. People who have good ideas are more worthy than those who do not							
23. A person doesn't need to be well liked in order to be happy							
24. Whenever I take a chance or risk I am only looking for trouble							

Time taken in minutes to complete the questionnaire

**APPENDIX 9      MPI**

## QUESTIONNAIRE 5

Below are a list of statements. Please indicate the degree to which you agree with each of the statements by circling your answer.

1. My parents set very high standards for me.

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
------------------	--------------------	-------------------	---------	----------------------	-----------------------	---------------------

2. Organisation is very important to me.

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
------------------	--------------------	-------------------	---------	----------------------	-----------------------	---------------------

3. As a child, I was punished for doing things less than perfectly.

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
------------------	--------------------	-------------------	---------	----------------------	-----------------------	---------------------

4. If I do not set the highest standards for myself, I am likely to end up a second-rate person.

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
------------------	--------------------	-------------------	---------	----------------------	-----------------------	---------------------

5. My parents never tried to understand my mistakes.

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
------------------	--------------------	-------------------	---------	----------------------	-----------------------	---------------------

6. It is important to me that I be thoroughly competent in everything I do.

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
------------------	--------------------	-------------------	---------	----------------------	-----------------------	---------------------

7. I am a neat person.

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
------------------	--------------------	-------------------	---------	----------------------	-----------------------	---------------------

8. I try to be an organised person.

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
------------------	--------------------	-------------------	---------	----------------------	-----------------------	---------------------

9. If I fail at work/school, I am a failure as a person.

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
------------------	--------------------	-------------------	---------	----------------------	-----------------------	---------------------

10. I should be upset if I make a mistake.

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
------------------	--------------------	-------------------	---------	----------------------	-----------------------	---------------------



**11. My parents wanted me to be the best at everything.**

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
---------------	-----------------	----------------	---------	-------------------	--------------------	------------------

**12. I set higher goals than most people.**

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
---------------	-----------------	----------------	---------	-------------------	--------------------	------------------

**13. If someone does a task at work/school better than I do, then I feel as if I have failed the whole task.**

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
---------------	-----------------	----------------	---------	-------------------	--------------------	------------------

**14. If I fail partly, it is as bad as being a complete failure.**

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
---------------	-----------------	----------------	---------	-------------------	--------------------	------------------

**15. Only outstanding performance is good enough in my family.**

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
---------------	-----------------	----------------	---------	-------------------	--------------------	------------------

**16. I am very good at focusing my efforts on attaining a goal.**

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
---------------	-----------------	----------------	---------	-------------------	--------------------	------------------

**17. Even when I do something very carefully, I often feel that it is not quite right.**

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
---------------	-----------------	----------------	---------	-------------------	--------------------	------------------

**18. I hate being less than the best at things.**

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
---------------	-----------------	----------------	---------	-------------------	--------------------	------------------

**19. I have extremely high standards.**

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
---------------	-----------------	----------------	---------	-------------------	--------------------	------------------

**20. My parents have expected excellence from me.**

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
---------------	-----------------	----------------	---------	-------------------	--------------------	------------------

**21. People will probably think less of me if I make a mistake.**

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
---------------	-----------------	----------------	---------	-------------------	--------------------	------------------



22. I never felt as if I could meet my parents' expectations.

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
---------------	-----------------	----------------	---------	-------------------	--------------------	------------------

23. If I do not do as well as other people, it means I am an inferior human being.

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
---------------	-----------------	----------------	---------	-------------------	--------------------	------------------

24. Other people seem to accept lower standards from themselves than I do.

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
---------------	-----------------	----------------	---------	-------------------	--------------------	------------------

25. If I do not do well all the time, people will not respect me.

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
---------------	-----------------	----------------	---------	-------------------	--------------------	------------------

26. My parents have always had higher expectations for my future than I have.

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
---------------	-----------------	----------------	---------	-------------------	--------------------	------------------

27. I try to be a neat person.

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
---------------	-----------------	----------------	---------	-------------------	--------------------	------------------

28. I usually have doubts about the simple everyday things I do.

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
---------------	-----------------	----------------	---------	-------------------	--------------------	------------------

29. Neatness is very important to me.

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
---------------	-----------------	----------------	---------	-------------------	--------------------	------------------

30. I expect higher performance in my daily tasks than most people.

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
---------------	-----------------	----------------	---------	-------------------	--------------------	------------------

31. I am an organised person.

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
---------------	-----------------	----------------	---------	-------------------	--------------------	------------------

32. I tend to get behind in my work because I repeat things over and over.

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
---------------	-----------------	----------------	---------	-------------------	--------------------	------------------

33. It takes me a long time to do something “right”.

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
------------------	--------------------	-------------------	---------	----------------------	-----------------------	---------------------

34. The fewer mistakes I make, the more people will like me.

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
------------------	--------------------	-------------------	---------	----------------------	-----------------------	---------------------

35. I never felt as if I could meet my parents standards.

Totally Agree	Agree Very Much	Agree Slightly	Neutral	Disagree Slightly	Disagree Very Much	Totally Disagree
------------------	--------------------	-------------------	---------	----------------------	-----------------------	---------------------

Time taken in minutes to complete the questionnaire .....

APPENDIX 10 DE GRASIA: STYIE 101. 101.

# QUESTIONNAIRE PS I

Here are a number of statements about personal characteristics. Please read each one carefully, and indicate whether you agree or disagree, and to what extent, by circling a number.

		Strongly disagree	Disagree	Slightly disagree	Slightly agree	Agree	Strongly agree
1.	I often put other people's needs before my own.	1	2	3	4	5	6
2.	I tend to keep other people at a distance.	1	2	3	4	5	6
3.	I find it difficult to be separated from people I love.	1	2	3	4	5	6
4.	I am easily bothered by other people making demands of me.	1	2	3	4	5	6
5.	I am very sensitive to the effects I have on the feelings of other people.	1	2	3	4	5	6
6.	I don't like relying on others for help.	1	2	3	4	5	6
7.	I am very sensitive to criticism by others.	1	2	3	4	5	6
8.	It bothers me when I feel that I am only average and ordinary.	1	2	3	4	5	6
9.	I worry a lot about hurting or offending other people.	1	2	3	4	5	6
10.	When I'm feeling blue, I don't like to be offered sympathy.	1	2	3	4	5	6
11.	It is hard for me to break off a relationship even if it is making me unhappy.	1	2	3	4	5	6
12.	In relationships, people are often too demanding of one another.	1	2	3	4	5	6
13.	I am easily persuaded by others.	1	2	3	4	5	6
14.	I usually view my performance as either a complete success or a complete failure.	1	2	3	4	5	6
15.	I try to please other people too much.	1	2	3	4	5	6
16.	I don't like people to invade my privacy.	1	2	3	4	5	6
17.	I find it difficult if I have to be alone all day.	1	2	3	4	5	6
18.	It is hard for me to take instructions from people who have authority over me.	1	2	3	4	5	6
19.	I often feel responsible for solving other people's problems.	1	2	3	4	5	6
20.	I often handle big decisions without telling anyone else about them.	1	2	3	4	5	6
21.	It is very hard for me to get over the feeling of loss when a relationship has ended.	1	2	3	4	5	6
22.	It is hard for me to have someone dependent on me.	1	2	3	4	5	6
23.	It is very important to me to be liked or admired by others.	1	2	3	4	5	6
24.	I feel badly about myself when I am not actively accomplishing things.	1	2	3	4	5	6



		Strongly disagree	Disagree	Slightly disagree	Slightly agree	Agree	Strongly agree
25.	I feel I have to be nice to other people.	1	2	3	4	5	6
26.	It is hard for me to express admiration or affection.	1	2	3	4	5	6
27.	I like to be certain that there is somebody close I can contact in case something unpleasant happens to me.	1	2	3	4	5	6
28.	It is difficult for me to make a long-term commitment to a relationship.	1	2	3	4	5	6
29.	I am too apologetic to other people.	1	2	3	4	5	6
30.	It is hard for me to open up and talk about my feelings and other personal things.	1	2	3	4	5	6
31.	I am very concerned with how people react to me.	1	2	3	4	5	6
32.	I have a hard time forgiving myself when I feel I haven't worked up to my potential.	1	2	3	4	5	6
33.	I get very uncomfortable when I'm not sure whether or not someone likes me.	1	2	3	4	5	6
34.	When making a big decision, I usually feel that advice from others is intrusive.	1	2	3	4	5	6
35.	It is hard for me to say "no" to other people's requests.	1	2	3	4	5	6
36.	I resent it when people try to direct my behaviour or activities.	1	2	3	4	5	6
37.	I become upset when something happens to me and there's nobody around to talk to.	1	2	3	4	5	6
38.	Personal questions from others usually feel like an invasion of my privacy.	1	2	3	4	5	6
39.	I am most comfortable when I know my behaviour is what others expect of me.	1	2	3	4	5	6
40.	I am very upset when other people or circumstances interfere with my plans.	1	2	3	4	5	6
41.	I often let people take advantage of me.	1	2	3	4	5	6
42.	I rarely trust the advice of others when making a big decision.	1	2	3	4	5	6
43.	I become very upset when a friend breaks a date or forgets to call me as planned.	1	2	3	4	5	6
44.	I become upset more than most people I know when limits are placed on my personal independence and freedom.	1	2	3	4	5	6
45.	I judge myself based on how I think others feel about me.	1	2	3	4	5	6
46.	I become upset when others try to influence my thinking on a problem.	1	2	3	4	5	6

		Strongly disagree	Disagree	Slightly disagree	Slightly agree	Agree	Strongly agree
47.	It is hard for me to let people know when I am angry with them.	1	2	3	4	5	6
48.	I feel controlled when others have a say in my plans.	1	2	3	4	5	6

Time taken in minutes to complete the questionnaire

## **APPENDIX 11 BACKGROUND INFORMATION FOR MAIN STUDY**

## INFORMATION SHEET

### Personal attitudes and experiences of illness

We are conducting a study to find out more about attitudes and beliefs of people with various illnesses. This is important because it may influence how people experience their illness, how symptoms are discussed and consequently what sort of treatment they receive.

In order to find out about peoples attitudes and beliefs towards illness the study aims to develop specific questionnaires. If you agree to take part in this study all you will be asked to do is complete a number of questionnaires about your personal attitudes.

In order to evaluate the new questionnaires we have to make a comparison with some that are already established and which cover a similar but not identical focus. This necessitates answering a number of questions which you may experience as repetitive and frustrating, however this method is vital to our research.

Completion will take about half an hour of your time in total. The questionnaires need to be answered in the order in which they appear but they need not be answered all at one time. We are interested in how long each questionnaire takes to complete, we would be most grateful if you could make a note of this, there is a space at the end of each questionnaire to fill in this information.

The results will only be used for research and will be kept confidential. No one other than the researchers will be shown your responses and you will not be identifiable in any published report. Questionnaires will be destroyed at the end of the study.

If you decide you can tackle this questionnaire package and take part in this study you are requested to sign the enclosed consent form before completing the questionnaires. This form may seem over elaborate but it is one we are obliged to use.

Your participation in this study will be *greatly appreciated*, however we would like to make it clear that taking part is entirely voluntary. If for any reason you do not want to complete the questionnaires, it would help us if you could turn to the second sheet in the package and give your age, sex and occupation. These details together with, if you feel able, a brief indication of the reason the questionnaires have not been completed, will help us in ensuring the sample of returned questionnaires is a representative one.

If you have any further enquiries about this study, please leave a message for on 01865 226247 during office hours.

Thank You

Ms  
Oxford Mental Health Trust  
Department of Psychology

Dr.  
University Department of Psychiatry



# QUESTIONNAIRES

(TO BE COMPLETED CONFIDENTIALLY)

It would help us if you could complete your age, sex and occupation even if you are not completing the questionnaires.

AGE:

SEX: MALE/FEMALE\*

\*circle as appropriate

OCCUPATION:

## IF YOU ARE COMPLETING THE QUESTIONNAIRES:

Before you begin please fill in the above information and the following Personal Information Sheet and Consent form. Please read the instructions carefully for each separate questionnaire as each one differs slightly. There are no right or wrong answers, it is your responses that we are interested in. We would also like you to make a note of the length of time that it takes you to complete the set of questionnaires. Please check at the end that you have filled in all the questionnaires.

## IF YOU ARE NOT COMPLETING THE QUESTIONNAIRES:

If you feel able it would help us if you could give a brief indication of the reasons.

## RETURNING THE QUESTIONNAIRES:

Once the questionnaires have been completed, or if you are not completing them please return the package to Catherine Dendy, Cotswold House, Warneford Hospital, Oxford, using the enclosed stamped addressed envelope.

THANK YOU VERY MUCH FOR THE TROUBLE YOU HAVE TAKEN.

## Personal Information

Please complete this general information form about yourself before proceeding with the questionnaires. This information is needed to ensure that the sample of returned questionnaires is a representative one.

Please state your ethnic origin .....

Marital Status.....please circle number below

- 1 Single
- 2 Married/ Co-habiting
- 3 Divorced/ Separated
- 4 Widowed

Highest Educational Qualification Achieved.....please circle number below

- 1 No qualifications
- 2 Apprenticeship
- 3 Up to 4 CSEs or 'O' levels
- 4 Five or more CSEs or 'O' levels
- 5 'A' levels
- 6 Vocational training (HND,HNC,BTEC,Diplomas)
- 7 University Degree (BA, BSc, etc)
- 8 Post Graduate Degree (MSc, MPhil, Phd. etc).
- 9 Other, please specify.....

Current Occupation (if appropriate) .....

Occupation prior to illness (if appropriate).....

If you have never worked please state your parents' occupations or your spouse's occupation, which ever seems most appropriate .....

Current Employment Status( if appropriate).....please circle number below

- 1 Full time work
- 2 Part time work, please specify number of hours per week.....
- 3 Student
- 4 Housewife/husband
- 5 Unemployed - currently seeking work
- 6 Unable to work/study due to illness, please specify length of time.....
- 7 Retired due to illness
- 8 Retired not due to illness
- 9 Other, please specify .....

For how long have you suffered from your current illness, in years .....

Thank you for answering the questionnaires.

Please check that no pages have been missed, and that you have noted at the end of each questionnaire approximately how long it took to complete.

We are interested in how it felt to carry out this task:

- 1 Did you experience concentration problems during completion of any of the questionnaires?

YES NO

If yes please indicate on the scale below how much these affected you:

Only a minimum amount

As bad as it could be

1 2 3 4 5 6 7 8 9 10

- 2 Did you experience memory problems during completion of any of the questionnaires?

YES NO

If yes please indicate on the scale below how much these affected you:

Only a minimum amount

As bad as it could be

1 2 3 4 5 6 7 8 9 10

THANK YOU VERY MUCH FOR THE TROUBLE YOU HAVE TAKEN.

PLEASE RETURN THE PACKAGE USING THE ENCLOSED STAMPED AND ADDRESSED ENVELOPE.

**APPENDIX 12     STANDARD CONSENT FORM**



# ROYAL COLLEGE OF PHYSICIANS CONSENT TO RESEARCH FORM

Title of project Personal attitudes and experiences of illness.

Name of responsible Investigators                      Dr  
   Ms

Psychiatric Research Ethics Committee Application Number                      96-16

Have you read the Patient Information Sheet?

*(please circle your answer)*

Yes/No

Have you had an opportunity to ask questions and  
discuss this study?

Yes/No

Have you received satisfactory answers to all your questions?

Yes/No

Have you received enough information about this study?

Yes/No

Who has explained the study to you?

Dr/Mr/Mrs/Ms

Do you understand you are free to leave the study

\* at any time

\* without having to give a reason for leaving

\* and without affecting your future medical care?

Yes/No

Do you agree to take part in this study?

Yes/No

Signature .....

Date .....

NAME IN BLOCK LETTERS .....

**APPENDIX 13     ETHICS APPLICATION AND LETTERS OF  
ACCEPTANCE**



**South Oxfordshire Community Mental Health Team**  
**Charter House, 14 Wellington Street, Thame, Oxon OX9 3BN**

**Tel: 01844 217446**

**Fax: 01844 217451**

4 April 1996

Clinical Tutor  
Univeristy Dept  
Warneford Hospital

Dear

**RE: ETHICS APPLICATION NO: 96-16**  
**COGNITIVE ASPECTS OF CHRONIC FATIGUE SYNDROME AND RELATED**  
**CONDITIONS**

Your study was discussed at the meeting of the Oxfordshire Psychiatric Research  
Ethics Committee of 2 April 1996 and it is approved in full

Yours sincerely

A handwritten signature in black ink, appearing to read 'David Geaney'.

**Dr David Geaney, Consultant Psychiatrist**  
**Chairman, Oxfordshire Psychiatric Research Ethics Committee**

Our Ref: DG/JC/96.16

20 May 1997

Ms  
Psychology Department  
Warneford Hospital

Dear Ms

Re: OPREC: 96/16 - Cognitive aspects of chronic fatigue syndrome and related conditions.

Thank you for your letter of 5 May 1997. I can give permission for you to approach in-patients with whom I have responsibility on Ward, and have a primary diagnosis of depression, subject to you confirming with the ward doctor (Dr [redacted]), and the nursing staff that it is reasonable to contact any specified individuals on that day.

Yours sincerely

*Alison Fletcher*

Dr David Geaney  
Chairman  
Oxford Psychiatric Research Ethics Committee

Chairman: Dr David Geaney



**CONFIDENTIAL**

**APPLICATION NUMBER** .../.....

**OXFORDSHIRE HEALTH AUTHORITY**  
**PSYCHIATRIC RESEARCH ETHICS COMMITTEE**  
**APPLICATION FORM (01/10/96)**

**1. Title of project** Cognitive aspects of chronic fatigue syndrome and related conditions

**2. Investigators**

	Principal investigator	Other key investigator
--	------------------------	------------------------

Name and title

Post	Clinical Tutor	Research Fellow
------	----------------	-----------------

Qualifications	MA, MRCP, MRCPsych	BSc
----------------	--------------------	-----

DHA contact	Hon.Senior Registrar	Trametes Department
-------------	----------------------	---------------------

Address for correspondence and phone number	University Dept Warneford Hospital 26467	c/o Dr Sharpe
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**3. Places where the research will be done (including other sites)**

Warneford Hospital, John Radcliffe Hospital and Radcliffe Infirmary, Oxford

**4. Starting date and duration of study**

To start on the 1st April or as soon as possible thereafter, to be completed 30 September 1996

**5. Arrangements for indemnity**

- (a) Through Oxford University.
- (b) Because Trust patients are included. A copy of this application will be sent to the Oxfordshire Mental Healthcare Trust.

## **12. Procedures**

### **a) Interviews and self-report questionnaires**

Patients will be subject to brief enquiry to ensure that they meet the relevant inclusion criteria and do not meet exclusion criteria. The rest of the assessment will be by questionnaire. Questionnaires to be used are as follows:

1. Beck depression inventory.
2. State rate anxiety scale. (Spielberger).
3. Self concept scale (Robson).
4. Autonomous personality questionnaire (Beck).
5. Multidimensional perfectionism scale (Frost).
6. Assumptions questionnaire developed by the investigators.
7. Ambiguous events questionnaire to detect bias in attributions developed by the investigators.

Both the latter questionnaires are modifications of those used by Dr David Clark and colleagues in their anxiety research. All non-standard questionnaires are attached.

### **b) Recordings (videotape and/or audiotape)**

No recordings will be made.

### **c) Samples extra to normal care (arterial, venous, urine, CSF, biopsies, etc.)**

### **d) Administration of radio isotopes**

### **e) Administration of X-rays**

### **f) Administration of substances or agents other than drugs (e.g. diets, physical agents such as heat, radiations, etc.)**

### **g) Genetic studies (eg: screening for inherited diseases, or studies involving the manipulation of human generic material).**

### **h) Other procedures (e.g. procedures from experimental psychology, psychophysiological tests, exercise tests, etc.)**

## **6. Aims of the project**

The aim of this project is to test hypotheses about the beliefs and attitudes of persons with chronic fatigue syndrome and the extent to which they differ from persons with depression and chronic neurological disease. Specific hypotheses to be tested are as follows:

Patients with chronic fatigue syndrome will

- (a) be biased against interpreting symptoms as evidence of depression or emotional disorder as compared with patients suffering from depression and patients suffering from chronic neurological disease (multiple sclerosis).
- (b) more likely to hold attitudes concerning the importance of high personal standards and emotional control.
- (c) will score higher on measures on autonomy and perfectionism than patients with depression or chronic neurological disease.

## **7. Scientific background of the project**

In the proposed study we will.

- 1. Measure biases in symptom interpretation in order to test the hypothesis that patients with CFS have a particular bias against interpreting symptoms as evidence of depression.
- 2. Directly assess patient's attitudes about standards, emotional strength and emotional control.
- 3. Test the hypothesis that patients with chronic fatigue syndrome score particularly high on the personality traits of autonomy and perfectionism.

## **8. Design of the project**

The study design is a cross sectional case control investigation. It will require the assessment of a sample of patients meeting consensus criteria for chronic fatigue syndrome, a sample of patients with major depressive disorder and a sample of patients with chronic neurological disease (multiple sclerosis).



9. Subjects

	CFS patients	Control patients I	Control patients II
Numbers to be studies (and sex ratio)*	20 (10 male, 10 female)	20 patients with major depressive disorder (10 male, 10 female)	20 patients with multiple sclerosis (10 male, 10 female)
Age range	18-50	18-50	18-50
Inclusion criteria	meet consensus criteria for CFS	meet DSMIV criteria for depressive disorder	definite diagnosis of multiple sclerosis of at least 6 months duration
Exclusion criteria	meet criteria for melancholia	meet criteria for melancholia	Significant cognitive impairment

10. Payment of subjects

None

11. Mode of recruitment

Patients with chronic fatigue syndrome will be recruited from a specialist fatigue clinic run by Dr Sharpe at the John Radcliffe.

Patients with major depression will be recruited from psychiatric outpatient clinics at the Warneford. If necessary, psychiatric inpatients will also be included.

Patients with multiple sclerosis will be recruited from a specialist research clinic at the Radcliffe Infirmary run by Dr Palace.

The names of potentially suitable patients will be obtained from the relevant hospital specialist and their agreement for the inclusion of their patient in the protocol sought. The GP will then be notified in writing to ensure they have no objection to the patient being included. The patient will first be approached by letter and then by telephone to ask if they are willing to participate.

The letter to the general practitioner is appended.



i) Substances to be administered

DRUGS	1.	2.	3.
Approved name			
Proprietary name (if any)			
Formulation			
Dose			
Frequency			
Route			
Possible side-effects (append details as necessary)			
Possible interactions (append details as necessary)			
MCA status and number. PL/CTC/CTX/DDX <sup>1</sup>			

<sup>1</sup> MCA = Medicines Control Agency; PL = Product licence (append a copy of the relevant data sheet);

CTC/CTX = Clinical Trial Certificate/Exemption; DDX = doctors and dentists exemption (append a statement on the adverse effects and long-term safety of the drug, and a copy of the certificate.

**13. Information and consent**

***/MAKE SURE SURE YOU HAVE READ THE GUIDELINES FOR APPLICANTS. REMEMBER TO ENCLOSE THE INFORMATION SHEET AND CONSENT FORM/***

Each subject will be given an information sheet describing the purpose of the project and what will be required of them (attached).

They will receive this together with their questionnaires but will not be telephoned for at least twenty four hours so that they have time to consider whether to give their consent. Written consent will be obtained using the standard form.

**14. Agreement of the responsible clinician**

The agreement of the responsible clinician will be obtained in every case and the initial approach seeking their participation will be by the responsible clinician.

**15. Informing the patient's general practitioner**

The patient's general practitioner will be informed (see letter attached) and given an opportunity to object to the patient's participation. The positive consent of the general practitioner will not be sought.

**16. Funding**

None

**17. Material gain**

None

**18. Confidentiality and data protection.**

All questionnaires will be regarded as confidential and kept in a locked filing cabinet. Data will be entered anonymously onto a computer and all data will be destroyed at the end of the study.


**THE APPLICATION WILL NOT BE ACCEPTED UNLESS SIGNED BY THE PRINCIPAL INVESTIGATOR AND COUNTER-SIGNED BY EITHER A MEDICAL CONSULTANT (IN THE CASE OF MEDICAL APPLICANTS OR THE APPROPRIATE HEAD OF PROFESSION WITHIN THE INVESTIGATOR'S CLINICAL DIRECTORATE (IN THE CASE ON NON-MEDICAL APPLICANTS). IN THE CASE OF APPLICANTS FROM THE UNIVERSITY DEPARTMENT OF PSYCHIATRY, THE APPLICATION SHOULD BE SIGNED BY THE HEAD OF DEPARTMENT).**

The information given on this application form is, to the best of my knowledge and belief, accurate. I have read the Guidelines for Applicants (valid until 01/10/96) and understand my obligations and the rights of the subjects to be studied, regard to the giving of information and the obtaining of consent.

Name of Principal Investigator

Dr. Michael Sharpe

Signature



Date

19th March 1996

I have discussed the project with the investigator, who is in my department (or speciality), and I support this application to the Psychiatric Research Ethics Committee.

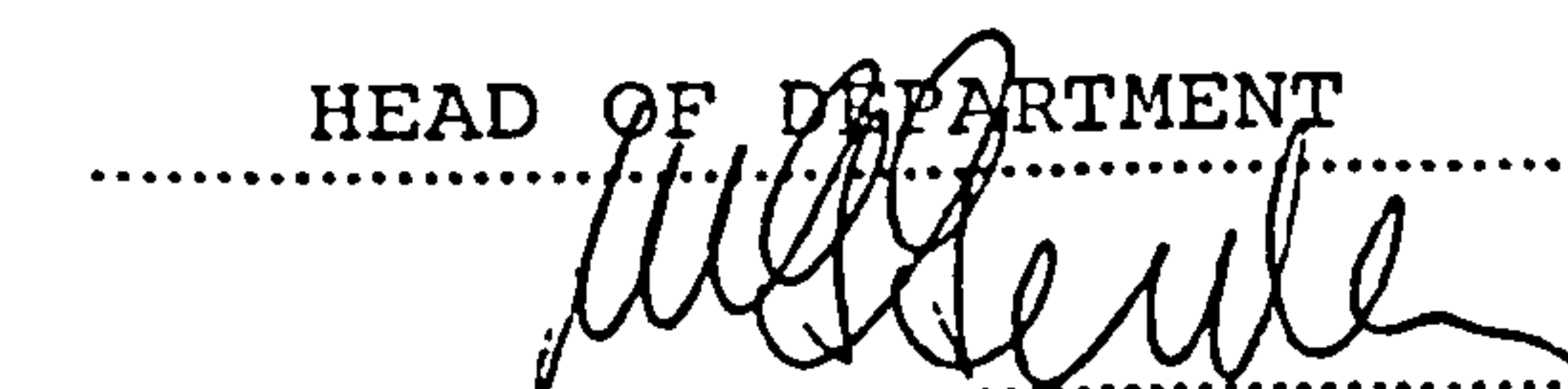
Name Consultant/Head of profession

PROFESSOR M G GELDER

Appointment

HEAD OF DEPARTMENT

Signature



Date

9/3/96

**APPENDIX 14      LETTER TO G.P.s**



Dr.  
Health Centre,  
Oxford,

Dear Dr. ,

0/0/97

Your patient: NAME,

D.O.B

Address:

is being asked to participate in the research study described below:

**OPREC: 96/16      Personal attitudes and experiences of illness**

This study is being carried out by Ms. NAME of the Oxford Mental Health Unit, Department of Psychology under the supervision of Dr. NAME of the University Department of Psychiatry.

The aim of his study is to determine personal attitudes and experiences of illness in patients suffering from Chronic Fatigue, Depression and Chronic Neurological illnesses. These findings are relevant to a cognitive theory of the aetiology of Chronic Fatigue Syndrome.

The only demand made on the patient will be the completion of a number of questionnaires (taking approximately half an hour in total).

The Information sheet given to participating patients is enclosed.

If you know of any reason why the aforementioned patient should not participate in this study I would be grateful if you could inform me by telephoning Oxford 226247 as soon as possible.

Yours Sincerely

Ms. NAME.  
Clinical Psychologist.

**APPENDIX 15      MAIN STUDY CATEGORIES FOR OPEN ENDED  
ANSWERS FOR IS-CFS**